

CDC/ATSDR Tribal Consultation Session
8/13/14
Grand Traverse, Michigan

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Lt. Governor Jefferson Keel: It's a beautiful day outside. I got here day before yesterday. I left Oklahoma. It was 96 degrees, sun shining, and I get to beautiful Traverse City, Michigan and it's about 50 degrees, raining. So yesterday was cold and wet, but today, it looks beautiful. And we're stuck inside. But I do want to thank you for being here this morning. We're going to have a great day. As our custom, before we do anything of importance, we go to our creator and I've asked Cathy to give us our morning blessing. Cathy?

Opening Blessing

Lt. Governor Jefferson Keel: Thank you, Cathy. Once again, welcome. It's our final day here, and today we're going to have a number of things on the agenda. We do have a busy agenda. If you'll look at today's agenda, you'll see that we have a couple of updates. We have native specimens discussion at 10:00 a.m. At 11:00 a.m., we're gonna talk about the environmental health think tank, and then we'll go to lunch. After lunch, we'll begin the tribal consultations and those are located in your binder here. We will begin that at 1:15, and we'll follow that schedule. And at that time, we will update everyone on the rules and how that's going to take place so that there's not any confusion because we may forget between now and 1:15, what's really taking place. So with that said, I do want to kind of update those who were not here. We did have a tribal caucus this morning, a meeting to visit about some things. One of the - just so that the - our federal partners understand, we weren't talking bad about you, we weren't holding secretive meetings. But we did visit about some things that we believe are important. One is making sure that the members of the advisory committee are prepared when we come to these meetings well in advance, we're up to date on the activities and issues and concerns of our respective regions. So we'll talk a little bit about the agenda development and how we'll do that. We'll also talk some about the CDC priorities. There are several of us who serve on the STAC, Secretary's Tribal Advisory Committee, in looking at the issues and concerns of all the other agencies. One item that is missing is the CDC priorities, so we're gonna make sure that we get those updated so that when you come to the STAC next month those will be included. So there were a number of other things we'll visit about that in the coming weeks. I'll get with Chester and we'll begin to move forward and I think we'll have a real positive effect. Some of us are new on this, we've got some new members, and so we'll make sure that we're fully prepared to engage at the next meeting. With that, I'm gonna ask for the Office of the Director update.

CDC Office of the Director Update

Dr. Ileana Arias: Thank you and good morning to all. Judy is going to be giving you a update and overview of some of the activities that are taking place in OSTLTS, which is more I think your main two discussions that we're going to be having later in the day. What I wanted to do was just provide an overall framework, or context if you will, of what is happening at the agency overall, what are the priorities for the agency that then is the context in which some of the decisions that we are going to be making about how it is that we actually protect and improve the health of American Indian and Alaska Native

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populations within that general framework. One of the things that we have decided at CDC is that regardless of the program, regardless of the community that's targeted, there are several things that we have to make sure that we do in order to be effective and in order to really have a significant impact. The first of those is making sure that we support and continue to strengthen epidemiological services and lab services. That goes without saying. And surveillance, of course. If we don't know where it's happening and who it's happening to, then we have - don't have a chance of making a difference. In addition to that, the second most important thing we can do is make sure we support state, tribal, local organizations, health organizations, especially government organizations. We're a national - we're a national federal agency. We actually don't do the prevention work that's necessary in order to change that population health. We have to put information and tools into the hands of people at the local level who can do that and that's where the partnership and the collaboration with you comes in. In addition to those two, we also want to make sure that policies that either are specific to health or policies that have an impact on health, like transportation policies, for example, are guided by the best possible evidence, by the evidence that's available in order to ensure that those policies are going to have the desired affect, number one, and not have unintended consequences as a result of, again, not being guided by what we know is happening, what we know is effective, and could make a significant difference.

We also then are committed to making sure that we support global health security in order to prevent either the importation or the exportation of diseases across borders to maintain health and save lives. And then lastly, we want to make sure that at any point in time, we're focusing on the leading causes of death for people in the United States and making sure that we're investing appropriately to address what the most significant vulnerabilities are. In the interest of doing that, we have looked at all our programs. We did this about three years ago now—three and a little bit years ago—and some of you are familiar with this. We identified what we call winnable battles. That is areas of health that have exert a significant burden on the health of people in the United States, but more importantly than just the burden, also areas where we know that there are effective interventions, we know that there are things that can be done, and there's some political and social will to actually be able to implement those effective strategies and programs to prevent. So the six areas that we've identified are tobacco use, healthcare associated infections, teen pregnancy, nutrition, physical activity, obesity, and food safety, motor vehicle injuries and HIV infection prevention. This is - these are areas that are significant for just about every person living in the United States, either directly or indirectly, and we're committed to making sure that, again, for the United States generally at a population level we make a significant difference. We also know that unfortunately in most of these, if not all of these, there are disparities - significant disparities, so not all communities are affected equally. The burden is not the same in all communities and the ability of communities to respond effectively to prevent these causes of death and illness and disability are not the same. And so one of the things that we're very careful to do is as we strategize for how it is that we approach our work with each of these winnable battles, what are the disparities that exist, what are the things that need to be done in order to address those disparities directly. One of the things that in addition to, and by the way, I should say that I've been at CDC now for 12, 13 years and since I've been there, this is the first time that we actually, as an agency, have gone on record what are the things that we are going to prioritize, what are the

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things that we are really going to get behind and make a difference and given ourselves an amount of time to do that. So for the winnable battles, we said we are going to do a full court press on these areas for the next five years. Perhaps more different, I guess, than identifying those areas is not only identifying those areas and how it is that we're going to address these areas, but then we said we're gonna hold ourselves accountable and we're gonna do it in a transparent way. So that we actually then came up with metrics that we were going for, targets that we were shooting for in each of these areas, and then monitoring how effective we're being over time in making a significant difference. In this past December – December of last year, we actually then published a dashboard, if you will, to show what progress we're making in each of these areas. Fortunately, in a significant number of these areas or the metrics that we set up, about half of them we already have accomplished the targets that we set out to accomplish, which is great news. In a significant other – about another third, we are on target to accomplish what we set out to accomplish, and unfortunately, there are some areas, the ones in red, where we have not done as well as we wanted to, where if we don't do something differently, we're not going to meet the targets that we set out to meet. So what we're doing now, what we have been doing, is trying to figure out why we have not made that progress. Is it because the strategy is wrong or is it because the implementation of those strategies is not working, and then making mid course adjustments that are going to be necessary in order to get some movement in these areas. And not only are we holding ourselves accountable for this but we're also trying to guide others in terms of what it is that they can do.

So in addition to monitoring our progress in these areas, Judy's office also puts out a Prevention Status Report, the PSR, for states to actually use. And what that does is it identifies policies that can be implemented at the state level, at the tribal level, at the local level, that creates a context in which the strategies that are effective for preventing a lot of these areas are going to be able to be implemented and are going to succeed. And so that has been available as well and we provide then an annual report on how it is that states are doing. In addition to the progress that we're making ourselves in terms of what we set as targets for CDC, states also have been showing significant improvement and impact in the efforts that they're making to address each of these areas. So we're happy to say that we have saved lives, we've prevented illness and improved the quality of life, as you can see by the progress that we've made, but we know that there's significantly more that we can do. In the context of identifying those six winnable battles, there are things that are emerging as higher burden than we had anticipated, things that we are identifying as possible to do for those areas so we actually have expanded that list of six areas for winnable battles and there are three that we've added. The first of those is prescription drug overdose. We have, for a significant period of time, seen a significant increase in unintentional overdose deaths in the United States. When you look closely, it is - that's primarily caused by drug overdose; opioids specifically and prescription opioids even more specifically than that. Unfortunately, there are significant disparities as well with Alaska Natives and American Indians having the second highest prescription drug-induced death rates after whites, a significant problem. Excessive drinking is another, which has been true for a significant period of time. But we have decided that it's time for CDC to actually focus on it a little more deliberately and proactively than we ever have in the past. And then the last is heart disease and stroke through the Million Hearts Initiative. Again, cardiovascular disease being the leading

cause of death for Americans and is starting to be true worldwide as well, and so doing whatever it is that we can in order to prevent those heart attack and stroke deaths. These areas are being now incorporated into the PSR and we're also providing information on policies that have been shown effective to create, again, context that not only have a significant impact on these things directly but then also support the implementation of other strategies that have a significant impact.

I'm going to talk about prescription drug overdose in a little bit and heart disease and stroke is familiar to you. I can answer more of that but I want to talk a little bit about excessive drinking since it's a little bit new for us and a significant challenge. The burden is huge, both financially and then socially and personally, and the devastation of excessive drinking to individuals, to families, to communities is sometimes immeasurable. A challenge for us is that excessive drinking does not necessarily have a home at CDC. It touches just about everything that we do. And so one of the things that we're trying very hard to do is making sure that as with cross-cutting things traditionally, that excessive drinking does not get lost in the process of trying to come up with a strategy for dealing with it. So we have put together essentially a team B, if you will, of SMEs, or experts, across the agency who have been charged for identifying what is it that we can do, what is it that we should do, very similar to what we've done with HIV, with teen pregnancy, etc., and then how is it that not only CDC can do that but how is it that we can empower states, tribes and local health departments to engage in these effective strategies. Not surprisingly, one of the first things that we can do, one of the things that is traditional for CDC is shining a light on the problem. Where is it happening to what the cost of that is and that is improving the data to support those programs to make those decisions. We also then have to do a little bit more on making sure that evidence-based interventions are being supported, are being implemented, empowering states, tribes and local communities to be able to then implement those evidence-based interventions and, again, disseminating as much information as is available to us to key stakeholders, including the public, in order to support the effort. It's going to be a significant—when I was in Injury and I used to be Director of the Injury Center, I used to think of alcohol as the tobacco of injury. And so dealing with excessive drinking is going to be a significant, significant challenge for a number of different reasons. One is it is a very normal behavior in our society, and dealing with something that's normalized makes it very difficult to then engage when that sort of normal issue becomes more pathological, if you will. In addition to that, there's going to be a lot of pushback because of that and other reasons. And again, we have to organize ourselves so that we can actually be effective and not let those things detract us from whatever it is that can be done.

What I'd like to focus now on is three areas that are sort of more forward looking, if you will. They're not necessarily things that are excessive burdens right now, though some of them are, but this is something that we are going to be facing in the future in making sure that we're not caught unawares for what we see as coming. We're also making these as priority initiatives for our budget and making sure that, unless there's a continuing resolution, that there is additional money coming in to support some of these areas that are woefully under funded now. The first of those is antibiotic resistance, second is prescription drug overdose, and then there's global health security. Antibiotic resistance is a significant, significant issue. We have about 23,000 people a year who

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die as a result of antibiotic resistant illnesses, and then that's in addition to that there's about 14,000 a year from *C. difficile*, which is becoming a significant, significant issue in health associated infections. It is a significant threat to economic instability and one of the things that we're very concerned about now, if you think about it, a lot of the improvements in health has been the result of antibiotics. It was the introduction of antibiotics that really made it possible for people to survive, especially children and older adults to survive a number of things that were just happening all the time and that was great. As a result of overuse of those antibiotics, we are working ourselves into a situation where we actually in a few years, in about ten years, are going to be in the pre-antibiotic age again if we're not careful. That is, we're going to be dealing with a number of significant illnesses for both children, adults and older adults that we will not be able to treat because the antibiotics that we have available to us are not effective anymore. That is very, very scary to us and it should be very, very scary to everybody else. We're not—I mean we are trying to scare people, not just so you can run and not do anything but because there are certain things that can be done. We know that we can make a difference. The first is stewardship in the use of antibiotics, making sure that they are used appropriately meaning that antibiotics are going to be used for things that will respond to antibiotics. We currently have situations where antibiotics are being provided for kids, for example, to deal with sore throats, ear infections, has absolutely no impact on that. But it feels good that your kid is being treated for something that is hurting them. We have to work on that and make sure that that's not happening. In hospitals and in-patient settings, it is also the case that antibiotics are being overused, again, in situations where they will not have an impact, or actually the wrong antibiotics are being used, or several antibiotics are being used when maybe only one or two are necessary in order to adequately deal with those infections. In addition to the fact that antibiotics are not being used appropriately, we want to make sure that, again, that stewardship is being implemented and that people are using antibiotics effectively. We do want to make sure that we identify antibiotic-resistant infections early so that antibiotics are not used and we use the proper medications for that. And then, of course, there's support in the development of new antibiotics, new medications that are going to be more effective than what we currently have now.

Prescription drug overdose, as I said, is a significant issue. It has become, over the years, a problem. In fact, for between the ages of one and 44 the leading cause of death as you know, traditionally has been motor vehicle related injuries. That is no longer the case. Motor vehicle deaths have been surpassed for ages one to 44 by prescription drug overdoses. So we have more people dying from overdoses- opioid overdoses in this country than we have dying from motor vehicle crashes. And that's the first time in the history of the surveillance that we've been doing that, that's been true of motor vehicle crashes. Part of that is because we've done a significant job in addressing and trying to prevent crashes and fatalities associated with those crashes but the other is the very steep rise in opioid overdoses. Not surprisingly, the costs are significant, not only in terms of those deaths and the cost associated with those deaths, but the cost associated with the addiction and the misuse that's associated with those and that precedes those fatalities. When we look at the data, it's clear that what has driven largely the increase in these overdoses is the significant increase in the availability of prescription opioids. Very similar to what we're seeing with antibiotics is inappropriate use of painkillers in managing pain and therefore the development and accessibility of

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opioid painkillers, which are incredibly addictive. The strategy that we've developed essentially is to focus on, again, making sure that pain is being treated appropriately and that we're reducing the use of prescription opioids to the extent possible, that we are implementing patient review and restriction programs to make sure that we prevent, for example, doctor shopping, that we're also looking at making sure that pill mills are closed down. We see that in areas where - and pill mills essentially offices that deal only in pain management where cash is how the medications are bought as opposed to through prescriber programs and other means. And so when we see those being removed from communities, a significant decrease in both abuse and in deaths associated with those opioids. We're also making sure that clinicians are aware of the dangers of using opioids, especially long acting opioids in emergency department areas and others. And then making sure that, again, the enforcement of policies that currently exist that have been shown to be effective in the prevention of accessibility and therefore abuse of opioids are actually being implemented. We now have several examples of states that have done an excellent job of availing themselves of all the tools that are available and starting to see significant decreases in their areas of overdoses and of the rate of abuse and accessibility to opioids in those communities. What we're interested in is making sure that those successes are widely disseminated so that others can entertain engaging in some of the same response in their own communities.

Finally, global health security. We have become an incredibly small world over time, meaning that what happens in one area very quickly becomes a problem for somebody else. No longer is it somebody else's problem and we don't have to worry about it. Mostly because of the changes in travel patterns, it is very easy to bring in and send out causes of disability, illness and death. One of the things that we have learned in trying to deal with that situation is that we can't fix it ourselves and so what we're trying to do essentially is try to—especially in low income and middle income countries—help them build systems - health systems that will allow them to manage those conditions in their country so that we don't have to respond to that. Otherwise, it comes to the point where we can't respond to it and the WHO can't respond to it anymore. So the idea is coming up with resources for countries to develop again, lab services, epidemiology services, and response services that they can engage in in order to address those outbreaks that we work very hard to contain so that they don't become a problem for us. One of those outbreaks, and an example—I'll just go through this. This is just giving you some—this is in your packet so you have the data in terms of exactly what the initiative that we're trying to engage in is. One of the—I think a wonderful illustration of why it is that we have to do this even though we are a domestic agency is what we're dealing with now and that's the Ebola response. We have been tracking Ebola—it started off as a contained and local outbreak and back in March we responded, as we always do, to those outbreaks. And it started to look like about in May that it was going down. We brought our people home and I shouldn't say it is because we brought our people home. We brought our people home because it started to decrease and then all of a sudden something happened and it started to increase again the rate - the number of cases, and it became out of control very, very, very quickly. At first, it seemed like it was just a problem in western Africa, but as you saw with the travel of individuals, everybody started to worry about the fact that we could actually import Ebola into our country. I'll talk a little bit more about that. It is a problem that has been significant and very challenging for a number of different reasons. A lot of it having to do with the lack of

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health - appropriate healthcare and infrastructure in these countries; therefore making it difficult to respond appropriately, to identify those cases early and to contain those cases in order to prevent the spread of disease which is what we always attempt to do and which is the way of effectively addressing Ebola. For those of you who may not know, Ebola is a serious illness. It's a hemorrhagic fever. It leads to not only severe illness but the fatality rate is very, very high. Unfortunately, there is no vaccine to prevent infection, and equally unfortunate, there's no medication that is effective in either treating it or curing infection once somebody does become infected. So it's very, very concerning. The only way to address it is to make sure that once somebody becomes symptomatic that they are isolated so that they don't contaminate – they don't infect somebody else, and then just basically using supportive medical interventions and therapy to make sure that the individual is comfortable and then increase rate of survival among those individuals. The difficulty in containing the disease or the infection in this area has to do with, again, that medical response. The inability to isolate people quick and to isolate them effectively so that others do not get infected. The numbers that you see on the board, this is a slide that we prepared last week. The numbers have gone up significantly, so we now have a total of 1,848 cases and 1,013 deaths in that group, and the numbers keep going up every year – sorry, every day. The response to this now, we have gotten involved again. We have currently 43 people who have deployed—we actually have 43 people in those three countries right now, and we're in the process of deploying another 22. We have 19 people who have already completed deployment and returned so this is a continuing effort with a significant investment in effort. And it's not just us. A number of individuals and organizations are also involved; the World Health Organization for sure, Doctors Without Borders and a number of other organizations who are involved in helping out both with the epidemiology and with the medical response to the problem.

One of the things that, again, traditionally things like Ebola, Marburg, etc., has stayed in country, has stayed in the areas where it occurred in part because they have been small outbreaks, but the other is because these individuals who have been affected have not traveled. That, in this situation, all of a sudden became a significant concern. As you saw, there were a number of individuals who then started to want to be going home that had been exposed and what problems associated with that. Although there is the possibility for individuals traveling in these areas to be infected and come to the United States or anyplace else and be infected, the probability, number one, is very low that will happen. The traveler advisory, essentially, is that individuals who have been exposed and in high risk situations and are showing symptoms, those individuals do not travel because they can infect somebody. If they're not showing any symptoms, they cannot infect somebody and so travel is okay, and they're doing a good job of assessing, and essentially the first thing to look for is their fever and using that as a way of deciding whether somebody can fly or not. The other is even if somebody does come to the United States, for example, and develops those symptoms, we do have hospitals that can set up containment situations so that that individual is isolated appropriately and would have good healthcare that would mean it is very, very unlikely that even if somebody developed Ebola symptoms here in the United States, that there would actually be an outbreak associated with that individual being ill. It's very difficult for people to accept that. It's very difficult for people to believe that, in part because the disease is so scary. But again, the probability of having this kind of a situation or even

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something less severe than this in the United States is incredibly, incredibly low, and we are very confident that not only us at the CDC but local hospitals, etc., can actually engage in the behaviors that they have to engage in in order to make sure that that doesn't happen.

So one of the things that then—I want to bring it back to what it is that we're here to talk to you about. A lot of the work that Judy is going to be talking about has been done in order to, again, improve and strengthen the relationship that we have and the effectiveness that we have in working with you to make sure that your communities are - benefit as much as other communities. But I just want to highlight one of the things that I think is critical in making sure that this time, if you will, we're going to make a difference and we're going to succeed in a way that we never have before. I mentioned in the beginning that one of the things we did with the winnable battles, which was radical for CDC, one is identifying those priorities, and two, committing to measuring the progress and making that transparent. And so one of the things that I think is - I'm most excited about, and I know it sounds simple, one of the reasons why I think we are going to make a difference is the Tribal Engagement Plan. We actually are identifying—and what I would like for us to see is what are the things that we need to focus on because it is a burden, but we know it can be done, we have those examples, we have some ability and some resources to do that. But then importantly, 'we're going to put that down on paper. We're going to put it down on paper, and we're going to routinely check in and see what progress we're making in those areas. If we're not making progress, flag it and say why? What is it that has to be done differently. So I applaud you for pushing us in this direction and collaborating with us in something like this because I really do think that this is going to make a difference. I am a clinical psychologist by training, I'm not a public health person. When I came to CDC, it was very clear to me the power of epidemiology, the power of surveillance, and what I mean by that is it's very clear to me that if it's not measured, it does not exist. If you don't count it, it doesn't exist. So although it sounds like paperwork, although it sounds like, you know, I'm engaging in sort of VIP epidemiology work, the counting, the measuring is key. If it doesn't, it just does not exist and it will go away and whatever it is that we focus on will be replaced by the new flavor of the day, if you will, if we're not measuring it, if we're not monitoring it, if we're not looking at why are we going in a certain direction, whether it's up or down. So I do thank you for your collaboration and your patience and indulgence in helping us, sort of, do this and working with us to make sure that we commit all of us to making a significant difference, even if it's in a handful of areas, it doesn't address everything, but let's make those successes and then build upon those. So thank you for that and thank you for your time.

CDC Office for State, Tribal, Local and Territorial Support (OSTLTS) Update

Dr. Judy Monroe: So good morning everyone and thank you very much for that presentation Dr. Arias. I wanted to first of all just to add to what you said about if we're not measuring, we really don't have the impact. I'm a clinician, I'm a family physician by training, and in the world of medicine, if it's not documented, it didn't happen, in the medical records. So there's a corollary there that it really is important that we document

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and we measure, and we hold ourselves accountable. So I think you've heard those messages. I wanted to start, especially for the new members to the TAC and those with us today that are maybe not as familiar with CDC's organizational chart, you can see where Dr. Arias is. So we've been really privileged to have her with us for the entire TAC meeting, and she's going on the site visit tomorrow. She is our Principal Deputy Director working very closely with our Director, Dr. Tom Frieden. Below them, you'll see there are four deputy directors and they've got a red mark there around the box I'm in so Deputy Director for State, Tribal, Local and Territorial support. My colleagues that are other deputy directors, Dr. Chesley Richards, and I'll mention him again later but he is over the Office of Public Health Scientific Services, and then we have Robin Ikeda, the Deputy Director for the Office of Non-Communicable Diseases Injury and Environment Health, so you can see how CDC broadly has divided the non-communicable disease and then going to the next Deputy Director, Dr. Khabbaz is over the Office of Infectious Diseases. And then under them across those three deputies, there are a number of national centers, and that's what you'll hear a lot about, and then within the centers, there are divisions and branches. So there's a lot of depth underneath each of these national centers that you can see. You met Ursula Bauer yesterday with our National Center for Chronic Disease Prevention and Health Promotion. You met folks from the National Center for Environmental Health yesterday. We have the Injury Prevention Center, which Ileana was Director of before being promoted to the Principal Deputy Director a few years ago. We have Anne Shuchat is over our National Center for Immunizations and Respiratory Disease, and some of you may remember her from H1N1. She was quite visible during that time on the news. Beth Bell has actually been in the news recently along, of course, with Dr. Frieden with the Ebola, and she's over our National - it's the National Center for Emerging Zoonotic and Infectious Diseases. And then we can't leave out Hepatitis, HIV and STD diseases, so prevention of those diseases and that's Dr. Mermin. And then we have not reporting to me, so that's a little misleading there but under the box I'm in, we have the Office of Public Health Preparedness and Response, National Institute for Occupational Safety and Health, and then the Center for Global Health and under Chesley Richards, going back to him, the Center for Surveillance Epi and Laboratory Services as well as the National Center for Health Statistics. So you can see it's very broad that we have at CDC or all the different centers.

This dives down into then the office that I direct so that you can see where the Tribal Support Unit is and Captain Shaw is currently our acting director. You've met her here at the meeting. But just to briefly go through my office, under Captain Shaw, we have a Partnership Support Unit led by Sam Taveras, and in that, we have a partnership support and a cooperative agreement with the National Indian Health Board, as well as the Association of American Indian Physicians. We oversee about 23 or 24 national partners out of that Partnership Support Unit. And we do that - we're a cross-cutting office, and so we don't - all of our work is really done on behalf of the agency and all of those centers and institutes and offices that you saw on the first slide. We work on behalf of the CDC at large as well as then on behalf of all of our stakeholders out in the field, hence our name. And then we have a Policy Unit, Management and Operations, and communications is something that we continually strive to try to do a better job, especially reaching the field and, again, on behalf of all of our programs across CDC. My Deputy Director is Steve Reynolds but under there, we have Craig Thomas who

directs the Division of Public Health Performance Improvement. That's where accreditation is housed for the agency. We oversee the accreditation. Some of you are familiar with the National Public Health Improvement Initiative that is being phased out now because it was de-funded, but we had a four-year run with that. I know especially Cherokee Nation was one but I think we funded under that seven or eight of our tribes. So there are a number of things that that office does. That's also the office that does the Prevention Status Report that was mentioned earlier. So there's a major amount of work there. And then I'm gonna mention more about our Public Health Associate Program led by Heather Duncan. We do have - we had a Field Services Office that we just changed the name to Stakeholder Outreach and Engagement Unit and the reason we've changed that name is because the world is changing, especially post the ACA, the Affordable Care Act, has changed a number of things. We're doing much more work now as an agency with the Centers for Medicare and Medicaid Services, especially the innovation center. So there are a number of funding opportunities that have come out of that to help advance the field, really to move away from fee for service in the medical world and move toward global payments or population health payments at large, and with that those changes—we're seeing something called the State Innovation Model Awards that have come out. By 2017, any state receiving funding will have to have a State Health Improvement Plan and that's something for all of you to be aware of that if your states are being funded through the innovation center and the new announcements for round two, if they fund the maximum number of states possible, will be up to 33 states that are in that game that are being funded that way. So be aware of that. One of the reasons our office is involved is because the state health officers or the Secretary of Health at the state level are required to lead that initiative. In fact, talk about first time changes and the C change is that the innovation center at CMS has invited the state health officers to come to the innovation center to present their plan and to vet that plan with them. So this is really big. And then our Public Health Law office as well. So that's what OSTLTS looks like and so you can see where the Tribal Support Unit is.

You already heard yesterday several folks mentioned about our Secretary's Tribal Advisory Committee site visit. We were very happy—I brought pictures to demonstrate that they were there and our colleagues from HHS, Liz Carr, was there, Stacy Ecoffey along with some of the members of the STAC. And they did get to visit the laboratories and so forth. The one thing I did want to mention is we started the day with—so on that very first organizational chart that I showed you and all of the CIO's, as we call them, our Centers, Institutes and Offices, we had leadership representing the entire agency around the table for the STAC members to ask questions. One of the things that we did take away from that visit was that they asked that they have a point of contact in each of the CIO's and so we are going to provide that. We're working on that now to make sure that it's very clear who that point of contact is that can be reached when there are questions. And then, of course, you can always come through the Tribal Support Unit for any help that you might need. So we'll be coordinating that across CDC, but it was a very lively discussion.

So some of the things that we're working on, just ongoing communication with the TAC, and this came up yesterday. The Tribal Epi Centers are an area of discussion. We were very pleased. Ursula Bauer and I, when we had our trip back in March, we attended the National Indian Health Board meeting that took place in Billings, and as

part of that NIHB meeting, we conducted the first listening session. And this is something I learned. I wasn't aware of the listening sessions that Indian Health Service has done for quite some time, so we learned about those and we conducted a listening session and we were very pleased that many of the Tribal Epi Centers and epidemiologists attended that listening session so we were able to hear firsthand about the need for further engagement at CDC and to the updated—and make sure that we understood the new laws that make the Tribal Epi Centers, actually public health authorities. So that was very educational for us. Dr. Bauer came back—she I know went directly to Dr. Frieden to talk to him about our conversations, sent him notes, and I've been in conversation with Dr. Chesley Richards that you saw on the slide before that's really over the portion of CDC that's cross cutting and has the National Center for Health Statistics as an example and really is the key individual to connect. They also have under Dr. Richards in his area, they have the EIS officers, so that's one of our really premier programs, the Epi Intelligence Service where folks go out into the field and train to become epidemiologists. In fact, many of our leaders, Dr. Frieden was an EIS officer and he loves to tell the stories of his time and the investigations that he was—actually Ursula Bauer was an EIS officer, so it's a really premier program and a lot of leadership at CDC have come through that program before. So we'll have further engagement. I've had some discussions about making sure that we get Dr. Richards connected with the leadership for the Tribal Epi Centers to have further dialogue about how we can advance that work. Some of the work also, speaking about the Tribal Epi Centers, you know, many of the issues that we know are of concern are cancer, hepatitis, tobacco use, vaccine preventable diseases and STD program issues. Colorectal cancer screening is one where there's been a nice partnership in the Alaska Native people that have really the highest colorectal cancer rates of any racial ethnic group. Of course, the population resides in really remote communities distributed over a very vast state, obviously, and so there's been funding from the CDC Division of Cancer Prevention and Control and technical support, then, from the Indian Health Service Division of Epidemiology, that Alaska Native Tribal Health Consortiums. Alaska Native Epidemiology Center is also involved with this, so there's been a nice partnership leading a variety of projects aimed at increasing the colorectal screening thereby decreasing colorectal cancer among Alaska Natives. So that's one specific area.

The engagement plan, Dr. Arias I think has already gone over that quite nicely and you've heard the commitment from the OD at CDC about this engagement, so we will be advancing that and thank you for your input at this meeting regarding how we can continue to advance and improve the documentation to keep all of us accountable, so certainly appreciate that. I wanted to mention we are trying to get to Indian Country more. I mean there's nothing - it's such an important learning opportunity for us and very honored to have been invited to Lame Deer, Montana to be part of the NIHB board and held their meeting in Lame Deer back in March. Ursula and I, actually, were able to attend that meeting and, as part of that, had a chance to visit the Lame Deer Health Center. A few of my reflections from that, the things I was really pleased about when I saw the health center at Lame Deer, the facility was quite nice and they had a really nice dental—I was impressed with the dental services that were available. I was impressed with their electronic health record and the commitment to electronic health records which means – that means a lot of data is collected and organized, and they had the physicians—Ileana probably hasn't heard this but the physicians - they had posted their

monthly metrics about whether or not they were screening. They were - talk about accountability. That was very transparent accountability with the records of the physicians, and we were all able to see how well they were doing with their own work. So that part was very positive. The part that - they have a behavioral health there in the center, physical therapy and optometry, but when we got to the behavioral health area, the stories that we heard about the methamphetamine and how the drug cartels—I don't know that I had truly appreciated how the drug cartels have targeted Native Americans and so that was really heartbreaking to hear about infants being born that were addicted or young teenagers or young adults—the devastation of the meth addiction. So I will tell you that hit hard and just the disproportionate—understand now that that really has disproportionately been - has impacted the Indian Country. So got pretty upset over that one. So I think it's really important that we do get to Indian Country and certainly really appreciate the invitations to come visit. Also had the chance to - I had a chance to speak at the National Indian Health Board, and of course as many of you know, Councilman Jace Killsback, there - he's northern Cheyenne. So it was a really good meeting I thought at the Public Health Summit in Billings.

I wanted to talk a minute about the Public Health Associate Program. You've heard us talk about this and we continue to grow this again for the new members of the TAC, this is a program that CDC has been growing since 2007. Historically, I should probably go back. CDC many years ago had a program where they trained public health advisors, and the public health advisors are really essential to the operations of public health. They're there to support the scientists and to help do the program management and they understand—many of them have trained in the field and have been at CDC and they understand the public health system. And so the program back in the - probably the early 90's had stopped and then over the years that ensued, people began to realize we were losing this pipeline. We didn't have public health associates because we weren't training them anymore. The CDC had really stopped that. So in 2007, there was a pilot program in Florida with ten associates. The next year they went to 27 associates. You'll see 2009 is missing because we didn't have funding in 2009 for the program, and then in 2010 - by 2010, OSTLTS had been established under Dr. Frieden's leadership, and we mobilized resources to be able to bring in 65 associates, the following year 64. Dr. Frieden gave us a stretch goal and said, well, if we've gotten this far, why don't we go to 100. And so we went to 100 by 2012 and this was - we were able to do this because of support across the CIO's across all of the agencies. So other entities, not just OSTLTS, have been supporting the growth of this. And then we were very happy that we reached 100 and then Dr. Frieden said, well, why don't we go to 200. Just about the time we thought we'd met the stretch goal, he doubled it and so we have been marching along. We went to 134 in 2013. We're on target to bring in 166 in 2014, and by 2015, our intent is to reach the 200 stretch goal. And then I may not ask what the next goal is. As you can imagine, this is a major undertaking to bring in this many associates. So what we do, individuals that have a bachelor's degree or a master's degree are eligible for coming into the associate program. They're CDC employees for two years and then we've got - it gets complicated that there's a title—is it title 5 that we're able to do that or title 42? I'm not the expert at the HR issues, but there's opportunity for CDC then to be able to hire them up to five years. But they come in, they have a two-year training program, and they're assigned to a health department or in the public health field and so they get training at CDC. We bring them all in, we do this massive summer training.

They have a supervisor at CDC, they have an onsite supervisor in the field wherever they have been placed. There is a curriculum. We have a number of benchmarks and metrics that they need to reach as they go through their training. But I think it's a very exciting program and with the growth it's giving us even more opportunities, so we are very interested in placing more in Indian Country. We have, as you can see here on the slide, we're in 33 states now. There are two tribes and two territories but with this number going up, what needs to happen is we need folks to apply so the host sites apply for the—yeah, it's title 42. All PHAP become title 42. Okay. But at any rate, they will come in and get this great on – hands-on experience is the main thing. So if you want to be a host site, you need to apply. Once a year we open up for host sites. Usually that's in late fall or January - early in the year that the host sites are applying and then we select host sites. We have students applying, obviously, and we get thousands of applications. I mean, this is actually - it's a competitive program, which is a good thing, but like I said, we are interested in bringing in more Native Americans both as associates and having more placements in the field. So we look forward to working with you on accomplishing that goal.

This just shows you the field staff. We also have a number field staff embedded across the United States, up to 646. This was as of December 2013. This is a little bit influx. Just as our field staff that are deployed globally, as you just heard from Dr. Arias, depends somewhat on the need. A couple of stories both from the associates and the field staff. So to give you an example or a little flavor for this, one of our associates was assigned to the Albuquerque area Southwest Tribal Epidemiology Center. Worked on the reservation to conduct tribal health survey, and the survey included categories related to healthcare access, specific diseases, health conditions and health risk behaviors. This individual then analyzed the data, used the statistical analysis software that she was learning about, and produced two reports to be presented to the tribe. So you can see it was actually this month presenting to the tribe. So a great experience for a young budding professional in public health. And then that data and reports that have been done by the associate will help the tribe determine health priorities and identify their assets and needs and leverage their resources for their priorities. Another public health associate assigned to the Public Health and Human Services Division of the Eastern Band of Cherokee Indians worked on reporting results of the tribal health assessment to the community planning for the Tribal Health Improvement Process, and those efforts led to an increase in community input, so it was nice, and we heard yesterday how important that is to have the tribal community have input and take things to the tribal leaders and to the community. And so they had more input for strategic planning and substantial strides towards national public health accreditation which then would certainly give them a longer term investment in their community driven tribal health system. So there's a lot going on. And then her work also with Cherokee youth garden at the Kittawah Mound generated discussion about food systems and increased access to local organic food and outdoor employment opportunities for young people, thereby reducing disease and diabetes in communities. So we've got associates that are doing some pretty remarkable work in the different areas that they're assigned. And then our embedded field staff, as this slide shows, they do a variety of work. We had a Public Health Prevention Service fellow assigned to the Environmental Health Support Program in the Division of Environmental Health and Engineering with the Alaska Native Tribal Health Consortium, and that individual led a project to build the capacity of tribal

environmental program to assess the health risk of private drinking water wells. And we heard yesterday from Environmental Health about the safe water. So anyway, to give you a little flavor of the type of work that they're doing. And then moving on, here's a slide that just shows some of the embedded staff that are working with tribes. I mentioned the EIS fellows. We have two. One in Anchorage, Alaska and one in Portland, Oregon that are in the field. The PHPS fellow—I think that's the one I was just mentioning that's in Alaska that had done the work on safe drinking water and then public health associates, we're - we have them.

Accreditation. I wanted to move to that just quickly. Many of you have heard about the health department accreditation, which became real and was launched in September of 2012. That's when they began to accept the health departments applying for accreditation and getting in the system. At this point in time, and this is as of August 5th so this does change on a daily basis, 194 local health departments, 26 state and 2 tribal health departments are in the system to become accredited. A total of those we now have—does this slide show how many are actually accredited? I don't have that readily available but the - what's interesting about this, if you go to the box on the population last updated, the unduplicated population that is now covered by accredited health departments—so we have a number of state health departments and local health departments that have become accredited, those health departments cover over 48, almost 49 million Americans and if you look at all of the health departments, the local, state, and tribal health departments that are in the system that are pursuing accreditation, it'll be over 204 million Americans. So this has really reached more than a tipping point, and then I think on the map here too you can see we only have a handful of states now that do not have anyone that has applied for accreditation yet. So the green states, there are either state or local health departments that are already accredited and the blue states have health departments, again, either state or local that have applied for accreditation or tribal. So just wanted to give you a quick update.

And then our Public Health Law Program. I mentioned that. This just gives you a sample of some of the things—oh, 44 are accredited, thank you. You're on the PHAB board, correct? Yeah. So 44 total health departments that have achieved accreditation, and there's quite a process for that, too, so, you know, it takes a little time by the time they apply. So Public Health Law Program, these are just a few examples of the work that they have done. They are available for technical assistance. This shows that they are in the process of giving technical assistance on tribal infectious disease laws, the Great Plains Tribal Chairman's Health Board did ask for that help. They did make a visit out, I believe, in - here we are - in Rapid City, South Dakota in May. It was sponsored by the Great Plains Tribal Chairman's Health Board and National Indian Health Board where they did invite our Public Health Law Program to come and give an introduction about what they could offer and then that's leading to this technical assistance that they will do. They've also done work with Tribal Emergency Preparedness laws, so they are a resource available for you. And just wanted to mention our Morbidity and Mortality Weekly Review, the MMWR, many of you are probably familiar with that. It's a publication that has come out of CDC for a number of years now under Dr. Frieden's leadership. They started doing a monthly Vital Signs Report of the MMWR and what we do in OSTLTS is a week after that report has come out on a high level issue—as an example, the winnable battles have all been covered in one way or another in the Vital

Signs. We then conduct a national call just to engage people around the discussion of the publication that came out. We always have subject matter experts that have participated in the writing and the publication itself, so you'll hear from the expert that's helped write the Vital Signs. And then we always highlight from the field a couple of individuals that are representing their jurisdictions where they've been successful in achieving some of the metrics that we want to achieve in whatever the given topic is. So we - I did want to call out, we had what I thought, one of the most engaging town hall teleconferences back in February when Caddo Nation of Oklahoma was represented and talking about child passenger safety. It was a state and tribal perspective but I'll tell you, really hearing about what had happened at the tribe and the successes they had and how they've gone about their work really stole the show that day. So again, this is one of those areas I would love to have more participation on the calls and these are some upcoming topics just to give you a flavor of some of the topics: obesity, hypertension, cardiovascular disease, motor vehicle safety. So they're all very, very important topics that we cover. And I think I've probably come to the end. Okay. I will stop there with my comments. Thank you.

Lt. Governor Jefferson Keel: I want to thank Dr. Monroe and Dr. Arias too for getting us back on schedule. You did really well. These are fascinating topics, somewhat above our heads here a little bit. Mine. I don't speak for anyone else. But I was looking at some of these slides, and, you know, I was wondering why we don't have anymore embedded in Oklahoma. We probably need to look at that. Where's our Oklahoma folks at?... Well, thank you for that. Yeah, we're about to go to break. Do you have a question?

Ramona Antone-Nez: Ramona Antone-Nez, Navajo Nation. I have a question, and thank you for that time, Tribal Leader Lt. Governor. Dr. Arias, your presentation on slide number 3, which has the 2015 targets. I'm curious if that's available and how do we access the targets. Thank you.

Dr. Ileana Arias: Yeah, it is available. We can send you the link. What we've done is we've posted the strategy for each of these areas, what the targets are and then what the accomplishments have been in addition to then the dashboards. All of that is available on the site that is devoted specific to the winnable battles and we'll send that link.

Director Cathy Abramson: I wanted to ask Dr. Monroe in regards to the Public Health Associate Program. Could that be automatic, that applications to tribal sites be approved and staffed by an associate?

Dr. Judy Monroe: I think what we can do, and I've been talking to staff about this. I believe when the host site - you're talking about the host site? When host site applications come in, I do want to take a hard look at those applications from the tribal sites because we do want to have more placements to the tribal sites. Was your question could we automatically approve it? Did you go that far? I thought I heard that. I'm not sure I can promise that we can automatically approve, but I think what we can do and should do is that all host site applications from tribal entities should be—we should take a hard look at those and probably maybe some negotiation would need to take

place because we do have to make sure that we have the assurance of a site supervisor and, you know, certain criteria that we need to have in place. But if that criteria is met, then absolutely, we should be placing more in the tribal communities. Just my feeling about this is with the growth of this program, with 200 a year, that means at any given time we'll have 400 in the field because it's a two-year program. To have 400 associates that are CDC employees, and they're very bright young minds. You know, they're energetic. Youth is a wonderful thing. And they - because of the nature of this program, this is such an opportunity for two-way communication for us to learn from the field and really have—because these are boots on the ground in the field with fresh eyes that are learning from the senior people that are there in those health departments, and they're there to learn. So I just think it's a wonderful opportunity. So I think for our engagement plan as we talked about engaging more with the tribes, this is an opportunity we do not want to miss, so we really invite those applications.

Director Cathy Abramson: Yes, and we sure like to help you get to 200.

Dr. Judy Monroe: You bet.

Lt. Governor Jefferson Keel: Well, thank you once again. We will take a break. We will continue at 10:00 o'clock. We're gonna hear from - about native specimens. We are officially on ten minute break, not 15, not 11.

END. (BREAK)

Lt. Governor Jefferson Keel: Okay folks, we're gonna – we're gonna get started again. Our presenters are here, so please take your conversations outside. That didn't work, did it? Okay, maybe it did work. Okay. No one went outside, though. Okay folks – we are back on schedule, and we have our presenters here. I'm going to ask Dr. Monroe to introduce them.

Native Specimens Discussion

Dr. Judy Monroe: Great. So thank you. So we're going to move next in our agenda to discussion on native specimens, and we're really pleased to have with us Dr. Doris Cook, to help with the discussion and Stacy Howard is Associate Director for Policy, Division of Laboratory, Policy and Practices at CDC and Judith – is it Giri? Giri? Good. Dr. Giri is specimen management, Division of Laboratory, Policy and Practices at CDC. And then Dr. Cook – some of you have met before from presentations – but is a consultant to them. So, take it away.

Lt. Governor Jefferson Keel: You have to hold it down.

Stacy Howard: Good Morning. Thank you, Lt. Governor Keel and Dr. Monroe, for that introduction. We are very pleased to come before you today to provide an update on our efforts to develop CDC policy for the management of biological specimens from Native American population. We - as Dr. Monroe mentioned - there's a three person panel here today, but more importantly, we're here to hear from you, to get your input as we move

forward in this very important process to both us and to you as well. I would like to first turn it over to Dr. Giri, who will speak about CDC specimens, and more in particular, specimens that come to CDC.

Dr. Judith Giri:My apologies. We'll start out a little bit to just describe what type of specimens we have and how we get them. The specimens in this context are representative samples of a subset that's submitted for examination or testing and can be anything from soil to air to a large variety of organisms including specimens that are from human origin. How specimens get to the CDC, they are submitted for diagnostic testing to confirm diagnosis. They come from a variety of public health clinics and from laboratories. They can come from outbreak investigations, as Dr. Arias has described earlier. They can be submitted for evaluation of some environmental exposure or they can be from a large variety of different types of surveys that are conducted in the business that CDC is doing. An example of a survey, a large ongoing survey that is ongoing for a long time is the National Health and Nutrition Examination Survey or called NHANES. And this program is designed to assess the health and nutritional status of adults and children in the United States. How the specimens are utilized, what they are needed for. They are – they have been utilized to determine public health policies such as lead levels in gasoline, which came from the NHANES study I just mentioned. They are used to identify their active agents, Norwalk virus, HIV, Legionella and so on. They are used to develop national standards, such as the growth charts for children, for example, that were based on NHANES. And they are also used very importantly for development of vaccines and diagnostics in variety of laboratory tests and standards. And I want to mention there that it is a great benefit for native communities to be represented in the set of specimens that are used for the development of such vaccines and tests and standards to make sure that they are represented is a real health benefit in being factored that set of specimens, with the understanding that these specimens will be treated in the appropriate manner and with engagement of the tribes that contribute specimens.

The many of the specimens that I have just mentioned, the type of uses of the specimens, are not research per se. Research in the sense of an IRB would describe research is for the purpose of gaining generable knowledge. This is for the most part done for the purposes of public health, which is a little bit different, for example, from a medical center, which is my background, from how specimens are used there; a lot of the specimens that are saved from - in such a center for research are used specifically for research. A lot of these specimens are used really for public health work of the type that we described. However, when the specimens are determined to be researched, then we follow all the rules and regulations of the HHS and for human subject protection, which follows all the informed consent, all the rules of how specimens are to be kept in.... So that's one of the challenges that I wanted to mention that to keep in mind that a lot of these specimens have a specific purpose, for a purpose of used for public health needs and not for research as such. I wanted to mention also that we are - we have taken note of all the specific questions that have been asked when we have presented about the specimens before. We are not ignoring these questions, it's just that they may not have the specific answers that are being asked for. We have specimens that are located in two different ways within the CDC. We have specimens that are within the laboratories, the active laboratories, and they have their own inventory systems, so we

have specimens in the central facility, which is called CASPIR, the CDC /ATSDR Specimen Inventory and Repository is what CASPIR stands for. And this center repository is under the oversight of the division we are—both Stacy Howard and I are in, as we have a lot of knowledge about it and we have talked a lot more about CASPIR but that does not represent all the specimens within the CDC. That's one of the challenges. The other challenge is that a lot of the specimens—talking about specimens that are at CASPIR—are quite old. We have some from the 60's and 80's. The earliest one I'm aware of is from 1962, and at that time a lot of the demographic information was not really collected in the level of detail of knowing exactly which tribe or which location the specimens were collected from so we may not have that information. In other cases, in the wisdom that usually is used for, protection of human subjects, specific information is not available to us to protect individuals. So then, again, we may not have the information necessarily to know the individuals from which the specimens were collected, or the exact tribes. We may know that they have been collected in certain areas, certain tribes have contributed to it. So that's another one of the challenges that I think we have mentioned before.

In general, I think the approach that we have described was to try to consider a policy of how we are going to deal with the specimens, which would include the full life cycle of specimens from the time they are collected to how they are handled to how they—if they are no longer needed, what will be done with them then, and create the policy that has this full life cycle of the specimens covered in a comprehensive way and then try to approach individually the specimens that we have. In order to do that, a specimen policy board has been convened and my colleague, Stacy Howard, will describe that.

Stacy Howard: Thank you. I recognize that there are probably several new members to the TAC that when we presented in February so in doing that, I just wanted to be conscious that there may be some things that we're providing an update on that perhaps we need to provide a little bit of greater context and background. So with that said, if there are questions that come about that maybe have been blast over, please, you know, we're really open and appreciative of any and all comments and questions that you may have as we move along this presentation and discussion afterwards. So in the governing, the collection and research and recognizing that all specimens that come to CDC are used for research. Stewardship, appropriate and respectful disposition of specimens from American Indian Alaska Native population. As Judith - Dr. Giri mentioned, CDC does have a policy around the management of specimens at CDC, and during the course of the development of that policy, it became clear that we needed to take deliberate time to understand the needs and requirements and expectations around managing specimens specifically from Native population. That said, that's where we are now, and the approach that we are taking—and when I say we, let me just kind of give a little bit of background. Dr. Giri and I, as Dr. Monroe mentioned, are in a center within CDC, it's the Center for Surveillance, Epidemiology and Laboratory Services. Dr. Richards - Chesley Richards - is the leader of that office in which that center resides. We are within the Division of Laboratory Programs, Standards and Services, and among our responsibilities for ensuring the quality and accuracy of laboratory testing is globally and externally as it relates to federal regulations that govern clinical laboratory testing, is that we also have specimen management responsibility. Dr. Giri mentioned that we have management responsibilities for the central facility in which specimens are stored

and careful stewardship off site, not within the laboratories. And we also have certain responsibilities as it relates to the CDC specimen policy board. That specimen policy board has a number of different responsibilities, one of which is to really look very closely at what would be such policy requirements around such specimens from Native populations. This is a joint effort with Dr. Monroe's office. We are been working very carefully to identify and engage stakeholders for information and sharing. This I believe it's the third time that the Native Specimens has been on the agenda of the TAC meeting. It is my hope and I hope that we are continuing the dialogue and process to move this forward to accomplishing the goals of the policy development process here. We're also looking to get information that may be going from external experts via a cooperative agreement that Dr. Monroe's office has with the American Association of Indian Physicians. You heard a little bit earlier about that. And Dr. Cook will provide a great deal of detail and information and updates as to their efforts in supporting and engaging communities with regard to supporting our policy development effort. And then she will also look at and provide input and share information that was gleaned through listening sessions that have been conducted since we last presented during the February TAC meeting. I think with that said, last - during the last TAC Meeting, we asked and here's what we heard. So we asked the questions, what are the expectations of Native American communities and how best can we address these expectations with the help of the Tribal Advisory Community. We believe we had very good dialog and information shared from you and we have captured it here, and please do let us know if we have accurately captured responses to the questions that were asked. I know there were a number of follow up questions that came out of that discussion as it relates to what do we mean by specimens, where do these specimens come from, why does CDC have them, and you know, what do we do with them. So we started off the presentation with Dr. Giri providing a little bit of context around what do we mean by specimens and how do they come to CDC and what really contributions those specimens have had to public health in general.

So what we heard is being accountable. We are holding ourselves accountable to making sure that specimens that come to CDC, that we provide appropriate stewardship for such specimens that are entrusted to us. What we heard is that there needed to be an appropriate individual as well as community consent where there is such a need to have IRB approval, making sure that that consent process is appropriate and addresses questions that individuals may not have as it relates to specimens that are taken from them. We also heard that we really need to have meaningful consultations, and it's not just about coming here, providing a presentation. We want to hear from you. We want to hear from you in terms of what are your beliefs and expectations to further guide us in our process. We also heard the need to be honest, and we are just as honest as we can be in this process. The only thing that I could say is that Dr. Giri and I are very sort of anxious about making sure that we follow proper protocol, so if we breach any protocol in terms of what's said or not, you know, chalk it up to it's within our heart to make sure that we're following proper protocol. But substantively what we're saying about the specimens, etc., we are very honest and want to continue to have open dialogue with you around information sharing and as well as transparency providing regular updates so you're providing an opportunity for you to ask questions of us, guide us in a direction that will ultimately lead to us accomplishing the goal of the project in a very meaningful way. We also heard respect the humanity and respect for spiritual and cultural

traditions. I believe there was a question asked of us during the February TAC meeting and when we talk about external experts, would we engage a traditional medicine, and yes, I can say that that is the plan to engage traditional medicine in terms of getting input, not only maybe for the experts, but as well as consultation during listening sessions, and I really will defer to that discussion to Dr. Cook. And then also, I've already mentioned stewardship. So I stop there, and I would like to turn it over to Dr. Cook at this point. She will also share with you information about what has been gleaned through other listening sessions with tribal communities, and we look forward to open discussion and dialog at the end of the presentation.

Dr. Doris Cook: I would like to acknowledge the Grand Traverse Band of Ottawa and Chippewa Indians, who've basically welcomed us and enabled us to move on their traditional lands. I'm here on behalf of the Association of American Indian Physicians, the AAIP, who is a partner in a cooperative agreement covering nine - nine projects. As a consultant on the Native Specimens project, I'm pleased to be able to share with you the project - information on the project, provide enough data on activities, to answer questions where I can, and to listen to your concerns and the advice that you may be able to provide on the project. The CDC's policy specimen board is charged with the development of specimen policy for all of CDC. This project will help to inform the specimen policy board's policy development process on relevant cultural and ethical aspects of the management of the American Indian Alaska Native specimen - biological specimens to help ensure that the policy that CDC develops is culturally relevant and consistent with traditional values and ethics. Stacy Howard has already addressed the lack - I believe - addressed the lack of Native-specific policy and it's our hope that this project is able to achieve its objective of helping to create a stable environment for ongoing CDC work involving American Indian and Alaska Native specimens.

It also helps to ensure that tribal support and involvement in the policy development initiative is garnered. We've adopted a bottom up strategy that starts with engaging tribal communities on cultural values and ethics. In order to ensure that the policy that CDC develops is consistent and respectful of tribal values and traditions, we first need to find out what's important to tribal people. A second component involves the development of background initiative group including traditional values and ethics, the legal landscape for specimen management, a review of international development and impact on Native specimens management, and a review of domestic and tribal initiatives that are designed to ensure that the external experts share a common understanding of the issues that they'll be deliberating. The EE, or External Experts, are individuals who'll be representatives of those disciplines and areas that ought to be involved in the discussion and will contribute their individual expertise for reports that are prepared for CDC.

Tribal communities will have another opportunity to weigh in on the report on the dialogues we're holding to see if we've got it right, if we've heard what communities have had to say on the listening sessions as well as the individualized reports that these external experts will be preparing. The last step involves providing CDC with the information from the dialogues that we are currently engaging in and the reports of the external experts so that they'll have the essentials to draft the policy that is respectful of traditional values and ethics in Indian Country. This novel approach for federal policy

development starts with the communities and the voice of the people to ensure that there is respectful engagement to tribal people, and that the policy that's ultimately developed is both usable and useful and gainfully the buy-in of Indian people.

Stacy spoke earlier to what we heard in February at the TAC meeting, and I'd like to briefly report on what we heard in three other listening sessions. The first was the Native Health Research Conference in Phoenix, Arizona. The second is at a listening session at the Denver Indian Center in Denver, Colorado. And the third was held recently at the Association of American Indian Physicians annual conference. Three different audiences but all similar perspectives. The top foundational values are ones that we might normally associate with leadership. They were at a different level than the individualized concerns expressed in the listening sessions. Some of the differences, respect for tribal sovereignty is one that the elected leadership was quite concerned with. There is a need to respect the tribal sovereignty, to respect humanity, to ensure that there is trust involved in the relationships between tribal communities and federal government and others, as well as respect for the spirituality and the connection that Native people have with their tissues and their bodies. And, of course, stewardship is one that often is presented in the leadership context. The leaders are stewards of the community, they are - they help to ensure that there is respect, honesty and there is information sharing. Those are largely the concerns that were expressed by this Tribal Advisory Committee.

At the three listening sessions that were held, some similar concerns were addressed - the desire to have meaningful consultations, the words that are presented by tribal communities are heard. There was individual level concerns around informed consent to ensure that individuals who are donating or providing samples have the information and education around the use, the storage and disposition of their tissues and samples. They also thought that there was room for the federal government to rethink its policy around specimen management, and naturally, there was a desire to have the world views, tribal world views, respected and considered. Dignity to personal samples. Individuals were concerned about the disposition of those samples, how they're managed and how they're ultimately disposed of. Individuals referenced body tissues that were taken ten years ago, and they have no idea what the use of those samples was—what the samples were used for and how they are managed.

We have developed project plans that initially span – that span a three-year period. The first phase includes project planning, commissioning of papers and the initiation of community dialogues. The papers are intended to provide a common understanding of the issues for each of the individual experts, who will be called upon to consider and deliberate some of these issues. Phase two is where we are now. It involves the continuation of the community dialogues and engagement, the identification of the external experts and the analysis of the background research, background papers. We are establishing a schedule of community and national events to participate in and gather community level information on values and traditions. While we're here at Grand Traverse, we are meeting with tribal representatives to ensure that the voice of the Odawa and Chippewa Indians of the Grand Traverse Band of Indians is heard and included in the reports that will ground the policies. We plan on engaging multiple communities where we can and where we're invited. There are multiple ways to getting

tribal input through formal listening sessions, through the distribution of questions with a drop-off or mail-back of questions, and other ways. Phase three involves the preparation of the individualized disciplinary reports, getting feedback on those reports and delivering the edited reports to CDC for use by the policy - specimen policy board to inform the development of the American Indian Alaska Native specimen management policy.

At this point, I'd like to present the listening session questions for your consideration and input, and then allow time for general comments and any advice that you would wish to provide to the project team. These are the questions that we presented to our - in the community dialogues and we would like you to consider the questions and provide responses where you would like to weigh in. The first question. What are some words that come to mind when you think about native biological sampling?

Lt. Governor Jefferson Keel: Dr. Cook, maybe I can go ahead and get started here. When we visit about native specimens, when we talk about - now that you've said biological samples, that's a little bit different when we talk about native specimens. You know, just the terminology is a little bit different. But throughout our history, Native Americans have been studied. We've had studies done on Native Americans all the way back to the 17th century, people wanting to study - wanting to know what the causes were of some of our diseases whether it be smallpox, syphilis, a number of things that Native Americans were studied for. As a matter of fact, there are today, remains of our ancestors that are sitting in cardboard boxes, paper sacks and plastic bags in repositories across the country, and those were never intended to be taken. Many of those have been removed from graves by archaeologists or government subsidized grave robbers. So I think the words that come to my mind is what's the purpose of taking these samples? What are they going to be used for and why store them for future if we know what we're going to do with them today?

Director Cathy Abramson: I just want to ask an overall question regarding this discussion because yesterday I heard that, you know, we have - this is part of consultation, correct? Okay, so if we're doing consultation, is it just amongst TAC members or because there are tribal leaders that are in the audience. Do we include them in - so that they can give input? Okay, good. That's good to know. I just wanted to make sure. So those tribal leaders in the audience can give input at this time. Okay, make that clear.

Dr. Doris Cook: There is an opportunity for the audience members to weigh in. We have a number of one-pagers that can be filled out by audience members, and also while we're here at Grand Traverse, we need to have a session. We're working on something with the elders here at Grand Traverse as well. Any of the members of the audience are more than welcome to take one of the one-pagers to provide that. I'm not entirely sure what the protocol is here now but that is one option. Chairman, I'm not sure how we would allow for feedback from the tribal members in the audience.

Lt. Governor Jefferson Keel: Well, I guess I'm getting a little bit confused on the consultation protocol itself. We're talking about doing a formal consultation on this topic, then I think that we need to go back and review what the procedures are going to be and how everyone is going to respond to that. So if there's someone in the audience who

does have a question, then they can address themselves at this time as a tribal leader, and we'll go back to addressing it in those terms. But I like your approach, there's a one-pager that they can take a look at that, fill it out, and then we can get their questions addressed.

Ramona Antone-Nez: Ramona Antone-Nez with Navajo Nation. Thank you to the presenters on the follow up to this important issue and subject matter. Members of the TAC and federal partners, I want to get some clarification about this particular topic in terms of my recollection, about a year ago we were preparing to have the TAC in 2013 August and that TAC did not happen due to—I'm not really sure but it didn't happen for the summer or the August session. So we prepared and we had the TAC in February 2014 and here we are at August 2014. As we were preparing for the September 2013 meeting that I'm recalling didn't happen. Can someone help me with that because we did go to Uncasville. Was that...? Okay, so aside from when and what was happening, the subject matter is my thoughts are that we were prepare - that the discussion is about past specimens that were collected and stored at the bank of CDC, and that the issue was that how and what is CDC going to do with those historical specimens and how are we going to approach those historical specimens. The discussions seem to be framing around are we going to return those back to the tribal nations and if so, how is that gonna happen? So now I'm hearing that—based on some recommendations are what are the current policies of specimens and how are they taken care of, which I'm understanding a lot of that was presented today. So I'm just going back to the initial framework and my thought processes about those historical specimens. And I understand that there's now the future. We continue to collect these specimens, and I can see that from here forward currently. I just want some clarification because my context is historical. You're talking, as presented today, as early as the 1960's when perhaps we were looking at specific cases and specific emerging infectious diseases at that time. So one of the other questions that I had was the inventory of what specimens are we talking about. There was a case study about two regions that had these in storage and what were we going to do with those. So I'm just trying to get some clarification. Thank you.

Stacy Howard: Normally my voice projects. Thank you very much for the question, and probably I think it would be helpful to provide some greater background because it sounds like when the topic of native specimens first came to the TAC, it was during the time that there was an introduction to our center and what our division does. And our division has, Division of Laboratory Programs, Standards and Services as we are named now, has primary responsibility for quality of laboratory testing. It is our division, it was communicated that really has primary responsibilities around laboratory regulations, around the quality of testing. Within the context of providing an overview of what our division does, it was mentioned, our understanding was it was mentioned, that we also have responsibilities for CDC's repository. And I think perhaps—and Dr. Giri and I were talking about it. It seemed, from our perspective, and please, you know, I appreciate the dialogue here—came to that we're banking specimens. And banking actually has a different connotation versus we're storing specimens that have been deemed appropriate for long term storage by laboratory programs. We don't go out and collect just for the sake of banking. So then, in looking at and listening to some of the concerns, we thought that perhaps, as we're taking a hope in developing CDC policy which we now

has and that policy addresses the standard operating procedures that laboratories must have, it addresses how we provide identified specimens so we know what we have. And then it also addresses, you know, disposition of specimens in accordance with regulations and in accordance to policies, and what we don't have, what those policy requirements about disposition, return and I know that was of very much concern of specimens from Native populations. So we're working now to address that so it's not just about what do we have because we know part of what we have. And when I say we know part of what we have, we know that within CASPIR, the repository, that there is a study, and Dr. Giri can talk about more about this, that we have become possession of from the Indian Health Service. So and that is very much, and I think it was communicated during the last TAC meeting, that those specimens are really then held aside until policy is put in place. There are some fine details about those specimens we don't know because the data may not have been collected back in the timeframe in which CDC became in possession of those specimens. So we want to make sure we do it right, and it's not - we heard that when specimens are collected, are we providing appropriate consent. We want to make sure that that process is appropriately addressed. After the last TAC meeting, a number of us met with CDC's Office of Associate Director of Science. We talked about specimens with CDC within the context of research, within the context of IRB. You know, what is it we know, what is it we don't know. And for those areas that we don't know, how can we get that information. So I hope that helps. I will stop there and I will have Dr. Giri to add to that

Dr. Judith Giri: I'd like to add two things. One is that I think that we have mentioned several times the Arctic Investigation Program that has the Alaska area specimen bank, and they have a protocol. It's not entirely applicable to everything we have, but it is a very nice model on how to develop a protocol with community engagement, and we were told that that protocol actually is available to any IRB here that would want to—they will be glad to share it. If they are approached, then that's Dr. Hennessy and Alan Parkinson, they have also published the methodology they have used. So we have an example of how to approach that and that includes, for example, things like what to do with specimens that could be harmful if returned because there were infectious agents, they may still be potentially harmful, and that group collectively came to the decision that that is not really a good idea to return them. And then the other—and we understand that there are different approaches and different tribes may feel differently about that. The other issue I mentioned that what we ran into is sort of a challenge, and we cannot necessarily identify individual tribes or individuals the specimens came from, and what we hope the policy will do is come up with some kind of acceptable method of maybe some ceremony, something that would be acceptable on how to deal with those specimens rather than trying to find the method of finding how to return them.

Ramona Antone-Nez: Thank you for that clarification Ms. Howard. I just want to—in order for me to conceptualize and process the remark or response to these questions that Dr. Cook has posed, I need to be in the right frame of mind of where are we going with this. Are we talking about the historical specimens or are we gonna look forward to specimens collected from here forward and what are the implications? So when you spoke about putting the specimens to the side and then developing the policies till we know what to do with them in an appropriate manner as they are in the repository—thank you for correcting me rather than saying bank, repository—till we know what to do

with that then we can proceed. So what I'm understanding right now, my frame of mind, if you would help me with this, is that to answer these questions for here forward specimens are biological samples but I also want to go back to what Lt. Governor talked about in terms of there's a difference between the specimens versus biological samples. Thank you for that clarification.

Stacy Howard: Yes, thank you and we're taking a holistic approach, but I think what we have concluded in terms of where we are now is looking forward, and of course what we end up with as far as policy, how can it be applied to what we currently have. That's the current thinking. And in regard to specimens versus samples, I can just share with you during the time in which CDC convened its internal work groups to develop the CDC specimen and sample management policy, that was quite a debate—discussion I should say—sample versus specimen, “potato versus pototto”. It has different meanings to different contexts. In fact, we had a discussion here, so sample may resonate with some, specimen may another. But in the end, we're talking about the same thing.

Lt. Governor Jefferson Keel: I don't want to sound argumentative, but when we talk about collecting samples, collecting biologic samples or specimens from Native Americans, I think it's important to put it in the right context of the purpose of why they're being collected, what they're going to be used for and then, as you mentioned, having a plan for how to either return them or dispose of them once the procedures is completed. But there also needs to be a timeline on when to expect - that is expected to be conducted. In other words, if there's an outbreak of some type of illness or sickness or disease, and we're looking for samples to study for research in the immediate future, then there needs to be some timeline on what we're going to do and not, as someone has mentioned, collect them and hold them because we don't know what to do with them. This is where we get a little argumentative. Some tribal leaders, some tribes and different cultures would say that they don't want anything to do with them once you've collected; others would say we want it returned immediately. And so there is a vast difference in some areas. So I think in terms of being respectful to all cultures that once you have a consultation, once we talk about what the procedures are going to be and we develop at least a system of processes that's going to be approved by the director or whoever in consultation, then that would be the procedure that's going to be used. You always run the risk of having someone being offended or whatever but I don't think that's a legal requirement. I think that's just something that needs to be a consideration. And so I think that when we talk about the words that come to mind, there are some things that are offensive. There are things that are insulting to native people. One thing that's insulting is the fact that tribal leaders may not be given the idea or be thought of that they have common sense, that they can think of these things on their own. We have to have some research lab to help them. There are native practitioners who could tell you what needs to be done with those already. And so that's where it gets a little insulting in terms of the native cultures and communities because we have some native practitioners who are very, very well advanced in this. And so I think we need to consider those also. And I know I'm taking too much time. We'll go to Beverly and then to Andy.

School Board Member Beverly Coho: Thank you. As mentioned, my name is Beverly Coho. I'm a Navajo. I represent the Albuquerque area. This is my first meeting. I don't

quite know what's expected, but I think I would be trying to answer that question literally, the one that's posed of us up there on what are some words that come to mind when we think about native biological samples. And first words that came to my mind was that there's a sacredness of body, mind and spirit among natives, particularly the Navajo people, and that there should be treatment of utmost dignity and respect for the specimens or the samples and that also there should be disposition of the samples or specimens, ceremonies. This might mean giving it back to the individual to do it the correct way. And this is all due to the connectedness among the body parts. What one does to one's self can carry infliction for a lifetime. So I see two worlds coming together and therefore there should be high accountability and that proper protocols are very important. And also don't be surprised if certain samples may be refused to be given, especially by the elders. So consent here is not an exception. Thank you.

Council Member Andy Joseph, Jr.: Badger is my name. Andy Joseph, Jr. from the Confederated Tribes of Colville. And Lt. Governor kind of hit it right on the nail right on the head about our people being studied. I kind of worry about some of these samples. They might have been taken from some of our people that were infected with smallpox. The government, the great country that we live in, handed out our people blankets with the smallpox virus on it, and my dad lost just about every one of his siblings from that. I don't know if any of these samples come from my aunts or uncles. My worry would be that if they are brought back, and they should be, that they're given back to us in a safe manner, where it wouldn't cause the infection to continue. And then the word consultation, I don't see this as a real consultation. To me, you know, not every - I don't think every tribe in the nation was contacted on this issue and, you know, they should be. Usually when we have consultation, my tribe is a sovereign government, there's 560-some sovereign nations within this nation that all need to be consulted with on these issues and they need to be respected in that manner. So I wouldn't call this a consultation. It is an advisory group, and I believe the members here would give good advice. At home when we have anybody come in to study our people, and they want - they have to get permission and ask to be approved by our council with filling out a research permit. And believe me, we've been studied like the governor said, and some of the prior to being approved by council through a research permit, there were times when people researched our people and made a big name of themselves and the outcome wasn't the real truth. And they've become famous people, you know, doctors with a big book. And so in part of our research permit process, we own the information that's collected. It isn't something that can just be freely given away. So, you know, I think for the future systems, if there are studies, I can see some benefit from studying if there is an infection that happens, that maybe there might be a cure to help our people but we would want to know in advance, and I think that maybe from this work group, we could look at having our advisory committee that helps us out, write some sort of a paper that would be given to our tribal members both on the reservation and in the urban settings stating what we feel is—I guess some kind of protection from people using their bodies for this type of research. It has to have some sort of a traditional—something that would explain to say if my kid was living in the big city instead of being on the res that he would know that his sample is a tribal sample and it can be brought to his attention that maybe his tribe don't authorize the use for any public issue. It should be returned to the tribe somehow. To me, I think that's really important. Back home when I was young, people was taking blood samples and stuff from me, and I don't know if they

were testing different infections on us when we were going to boarding schools. I know they were sterilizing some of the young ladies in the 70's and some of the doctors probably got big names for doing that. That part really bothers me about any research. Thank you.

Lt. Governor Jefferson Keel; Let me follow up on one thing that has to do with the consultation process. I think - and I just have a recommendation and it's based on some of what Andy was referring to. If we're going to develop a policy from CDC, or CDC is going to develop a policy that would address this, first of all, I'm reminded here that tribes are sovereign nations. CDC, you wouldn't attempt to develop one process that fits all the countries in Europe or all the different countries within Africa or any other place around the world. So in order to do that, I believe that CDC could put out - put forward a position or a proposed policy; we can get our technical advisors here to help us put together a position paper based on that so that we can come back and then we can send that out to Indian Country and let tribes across the country respond in their own way in how they would like to see this thing addressed. And then we can come back possibly at our next meeting which I believe is normally February in Atlanta, then possibly we could have something by then that gives us some time to work on this. And that's a proposal, a suggestion, and it could be modified however you want it. I just think it is time for us to get to that point so that we can develop one policy, get it out to Indian Country and come back and then suggest that to the native specimen policy board.

Chairman Herman Honanie: Thank you. Herman Honanie, Hopi Tribe. It's really an interesting topic. It kind of takes me back to years back when I first became a health director for the Hopi tribe, and not too long after that a lady and a gentleman came by asking for hair specimens to study albinism. And I thought, hey, that's an interesting topic, let's go for it, let's move with it, you know. But that was a long time ago, and of course, nothing happened out of that. I hope nothing happened out of that. But, you know, those are the kind of things that have been presented to our people at least over the course of the years, but more recently, certain events have taken place with other tribes where specimens were taken illegally or without their knowledge and court cases have come about to address those kind of things and I think maybe those are kind of things that we need to look at and research and find what really had happened and if there's any recommendations coming out of those cases regarding specimen. The other thing is that when Ramona was talking about task collections, and I think one of you mentioned in terms of returning them, what is the process of identifying specimens to respective tribes. I think that would really be a really challenging task to do so, and I think that when we're talking about things today, I just can't help but think about some of the discussions that are taking place, at least at my homeland with both council and within the program requirements to develop appropriate policies and IRB process for one thing, and maybe having as a tribe refuse totally to participate in a set research requiring specimens. And then my people are very, very suspicious that when an individual is killed, say maybe in a motor vehicle accident or homicide or things like that, they are very, very much opposed to an autopsy because of the suspiciousness of maybe a specimen might be taken without anyone's knowledge and where will that go and what will be its use. Things of that sort. So those kind of questions are always constantly up and about when it comes to specimens and so forth. Yet at the same time, maybe us as a younger generation, we have maybe a little better insight and understanding of research, and depending on maybe what the intent of a specific research is concerned,

or proposed this to identify. There may be a study, you know, heart disease or maybe diabetes or something like that, and maybe in that respect maybe there might be a little bit of support. But still, it's gonna require a lot of assurances on our part. A lot of the policies that need to be very, very specific and direct when it comes to specimen collection. So it's an interesting topic but I think we, as peoples - Native peoples in a sovereign government, we need to be assured. I really like and support the idea that a proposal be – I mean a policy be proposed and see where that leads to. And I think that each one of us tribal nations will probably come up with varying degrees of recommendations and so forth. But I think that's what has to be in order for a consistent and systematic policy to be applied in the right way. Thank you.

Lt. Governor Jefferson Keel: Well, I want to thank the panel for bringing this forward. We're not finished - Cathy?

Director Cathy Abramson: I'm sorry, I just wanted to say that I listened to Ramona and there are two things. Before - I do recall that we talked about historically what are we gonna do with the specimens, and at that time there wasn't any examples of what a sample is. So it was specimens. So is that the three things, or those are just examples of samples; blood, tissue, saliva- that's up there? Could there be more samples? Those three?

Stacy Howard: I think just to be sure we understand your question. On the slide, number two in parentheses; blood, tissue, saliva are given as examples of the types of specimen. If I understand your question correctly, you're asking what other types of samples could we be returned to?

Tribal Board Member Cathy Abramson: Yeah, because the first question was what comes to mind when we think about what Native biological samples are. And for awhile there, we had talked about the samples and specimens and, you know, in our minds, we're all thinking probably a lot of different things. I, not being—from what I know, it could have been, I told somebody, I said I just think of a brain inside of a jar or something, I'm not sure but, you know, from the Frankenstein movies you think of those things, you know. And so I am glad to see there are some examples and I'm not trying to be disrespectful and I truly do believe that we need to bring our people in that are—we have repatriation specialists within our tribes that could probably get involved and discuss and give us some input on what to do because it's to that point where we're not quite sure what to do. But when you talk about samples and like blood, tissue, saliva and say it could be their urine, you know, you pee in a cup or you poop in a cup or whatever, and I'm sorry but I would think that our ancestors would say well, just dump it, you know? And, again, there's a point of—so I would like to get our repatriations specialist to—because I'm sure that they have come - gone through a lot of discussions with a lot of things, but there are some things here that - where we may—there's a point of where we have to take a stand. But there's two parts here. One is historically and two, do we continue on. So that's what I hear and see.

Lt. Governor Jefferson Keel: I think we can do both in one document. I think that first of all, I believe in order to accomplish that, you would need some type of inventory of what CDC has in its possession, not necessarily by tribe or individual but at least the types of

samples that you have historically and where they were collected. So I know that you've got those records, surely you do. But if we had that historical data and then the policy would then cover what's going to take place from forward, how we're going to dispose of those already in your possession, how the future samples or specimens are going to be collected and the handling and disposition of those will be handled in the future. And I think we can handle that in one document or at least in one consultation session so that we could do that. And if we could get that done in the next two or three months, then if we could get that done maybe by November, that gives us a couple of months to get prepared for February for Atlanta. I'm gonna ask Dr. Monroe if that's possible, what your thoughts are.

Dr. Judy Monroe: So my thoughts, and you all can correct me, but I really like where you're going with this. I mean it sounds to me like—because we've had these discussions now for awhile, and it sounds like getting a draft policy in place with the background, so I'm envisioning having the background material so everyone understands what the issues are and historically what we have, and then having a draft policy. But I turn to you all—November, can we do that, especially with expertise because I'm also hearing that we have the individuals, the tribes have the individuals that have expertise already around this and enlisting their expertise in helping write a draft policy that then can go out to Indian Country certainly makes sense to me. I'm seeing heads nod so I think so.

Stacy Howard: Yeah, I would just add that, yeah, that sounds like a great plan, and it's just - the specimen policy board that was spoke of earlier is already been convened and they're working on a number of other related issues. So if we could get back to you in terms of the timeline given in how we can best meet the expectation and request of the TAC.

Lt. Governor Jefferson Keel: Okay, and we are running out of time. We're starting to get to the point where we need to—but I have a tribal leader in the back who wanted to say something. Chairman Payment.

Chairman Aaron Payment: So having a background in research and also expertise in Native American studies, one of the things that I'm concerned about is whatever policy you draft that you include a clear statement of not necessarily acknowledging or admitting or anything in the past, but there needs to be a statement so that we know in the future, you know, if you're talking about specimens that we have from 1962, that's quite a while ago, and so that's 50 years from now, how are these specimens gonna be used. And we know that from American Indian history that collection of information from Native Americans and the anthropologists that first did it in collecting skulls to see how much seeds fit in there to measure the capacity of the Indian brain, that going forward that we make some statement of the ethical use of the specimens. And I know that you said earlier that IRB, through the IRB approval, that all of that is protected as human subjects, but I just think that the policy statement should say something that reiterates in the past here's what was done, going forward here's how we will protect against that sort of thing because the whole question of intelligence and inherent intelligence, it seems like we're well past that but there are studies, burgeoning studies now that are looking at that again that we want to protect our samples from that. And then one question that I

don't know the answer to is I know that for people who believe our traditional way, felt like for me I guard my hair and so I don't know what the appropriate thing is for culturally after the specimen leaves if there's some ceremony or if there's something that should be done so that it no longer carries your spirit with it. So I don't know the answer to that but I know enough to know that I'm wondering about it. Alright, miigwetch.

Lt. Governor Jefferson Keel: Any other tribal leaders like to speak?

Loi Chambers: Hi. Loi Chambers, Grand Traverse Band Health Department. The question I have here is that it says what are your thoughts about samples being collected and stored in a specimen bank for some future use, and the question I have about that is storing specimens for future use and study for Native Americans and stuff like that, if it were to improve the healthcare for Native American-specific conditions, then I'm not totally against that as long as there is proper disposition of the specimen once the study is completed. So I just wanted to, you know, give my opinion on that. Also in agreement—back here with the inventory of those specimens that you currently have because it's going to be hard for tribes to decide on what policy to develop without knowing what kind of inventory that you currently have, the purpose of storing those specimens and if you were to keep those specimens, what future use would you have for them? Thank you.

Lt. Governor Jefferson Keel: Thank you very much. Those are the types of questions and responses I think that we'll get across the country from folks once this policy draft is generated. And then I know that we'll have some other folks who will develop recommendations on how we should proceed. So our initial draft then would be a draft that we're looking at to get out for recommendations.

Representative Chris Devers: Good morning. My name is Chris Devers. I'm the past chairman of the Pauma Band of Luiseno Indians in Southern California, and you're talking about the drafting of this policy. My question is, is since there are a lot of tribes in California that aren't here, how is this policy gonna be disseminated to the sovereign nations so that they have an opportunity to buy in or make a comment on. If not, I mean, you could always be one to say, hey, we sent it out to every recognized tribe in the country and take it from what it is. But that's my concern is you're talking about something that is a lot of our people may not even be aware of or not familiar with in the sampling process, and you go back to the 60's and there's - you can't account for where they came from. Are those people even still alive? And then what happens to them and those things. So there's, you know, I was sitting back there and there's a lot of questions, I think, that come about and I know in our area they're gonna have a substantial amount of questions. Thank you.

Lt. Governor Jefferson Keel: Thank you Chairman Devers, and the other - to answer I think part of your response would be how we get this out to all the tribes. I know that the National Indian Health Board and there's some other organizations that can help to make sure that every tribe receives and responds to this. As well as the TAC from each region can make sure that your regional Epi centers have this information and we'll get it out to all the tribes. So we can make sure that every tribe has an opportunity to review it

and receive it, and from the TAC, we can make sure that that's conducted. And I have one more. Shawna.

Secretary Shawna Shillal-Gavin: Shawna Shillal-Gavin from the Portland area. I wanted to just say a couple of things. I was not at the February meeting, but I called in. Andy and I were at another meeting and we both went and called in, and we were part of this discussion and my understanding, again, was—oh, and thank you for your presentation. My understanding, like Ramona's, was that it was historical specimens. So I went back to my tribe and contacted our repatriation people because that's one of the things that they would have a concern with. You know, some tissues are not an issue like was said so succinctly earlier, you know, just throw them out. But like if you're talking about bone and bone marrow, then there would be definitely—that would be really important. So I just want to concur with the recommendations that have been done. Clearly, it's been on the table for quite some time. I also concur with the setting of a deadline, and I'm looking forward to seeing the policy that you would like to put forward. Thank you.

National Tribal Environmental Health Think Tank and the National Center for Environmental Health (NCEH)/ATSDR Office of Tribal Affairs Strategic Plan Discussion

Lt. Governor Jefferson Keel: Well, thank you very much and once again I want to thank the panel for coming and presenting, and we look forward to seeing you soon. Thank you very much. Okay, moving right along. Is Annabelle still here? She didn't leave. Next on the agenda is going to be the National Environmental Health Think Tank.

Annabelle Allison: Annabelle Allison Good morning everyone. My name is Annabelle Allison. I am a member of the Navajo Nation, originally from a small community in New Mexico called Tohatchi. I've been with the National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry for about six years now. Thank you to the TAC for this opportunity to speak with you today. There were a couple activities that I wanted to provide a little bit more in depth overview of including this effort, this initiative that I have going called the National Tribal Environmental Health Think Tank and also a cultural awareness course that is being hosted through my office called the Working Effectively With Tribal Governments Training Course. I wanted to begin by going over a little bit of history of how my office was established. From my understanding, back in 1997, 1998, Health and Human Services, HHS, had a mandate that all of its agencies create tribal affairs offices. And at the time, CDC and ATSDR, the Agency for Toxic Substances and Disease Registry, were seen as separate entities. They were seen as separate agencies. And even today, ATSDR does get a separate congressional appropriation from - and CDC also gets a separate appropriation as well. So my office was, the Office of Tribal Affairs, was established in 1999 under the Agency for Toxic Substances and Disease Registry with the purpose of responding to tribal requests to investigate potential exposures to contaminants from hazardous waste sites. And at the time, the OTA was situated within one of our divisions under ATSDR and at that time, the division was called the Division of Health Assessments and Consultations. To also further explain that ATSDR has several regional offices throughout the United States and oftentimes, the ATSDR offices are in the same regional space as the EPA regional offices. And these regional offices have a long history of supporting

environmental health activities in tribal communities. So around 2007, an expert panel of tribal professionals convened to evaluate OTA's past accomplishments to discuss tribal health needs and to consider future needs and goals. Around this time as well between 2005 and 2007, ATSDR was being merged administratively with the National Center for Environmental Health or NCEH. And so the expert panel that was composed of tribal professionals from across the country made a recommendation to move the OTA from the ATSDR division to the OD or the Office of the Director for NCEH and ATSDR, and that is where the office currently resides now. I came on board in April 2008 and spent about 2-3 years essentially conducting outreach and gaining visibility for the office. The expert panel that I mentioned that had gotten together in 2007 also had a recommendation report that they had developed, and so I use that as my baseline or as my guide for moving forward and one of the recommendations within that report was to create a strategic plan for the Office of Tribal Affairs.

In 2010, NCEH/ATSDR supported a public engagement initiative called the National Conversation, and the goal of this National Conversation was to develop an agenda with recommendations to protect the public from harmful exposures, and the National Conversation included numerous stakeholders from across the country including academia, public health officials, community activists, etc. We sought to include tribal professionals in that National Conversation and part of the effort was to create six work groups that would focus on different topic areas and so we got tribal representation on each of those six work groups. So using the momentum from the National Conversation, I asked those six tribal representatives, who participated in the National Conversation, if they would join me in an initiative that became the National Tribal Environmental Health Think Tank. And at the time, the primary purpose of the think tank was to help to inform my office or to inform the development of a 3-5 year strategic plan for my office. And part of the reason why I wanted to come up with this plan was because of the past restructuring and also the personnel turnover that had occurred in previous years prior to my coming onboard. And so it became evident that the OTA really needed to move forward with new priorities in a sustained and focused manner. So the membership – so with the six originating tribal professionals who joined, I also recruited six additional representatives for a total of 12, who represented cross disciplinary diversity and job experience, rural urban representation and also geographic diversity. The members also are versed in tribal public health, environmental health, epidemiology and environmental science. Because the first year of the think tank proved to be a successful mechanism for sharing of ideas, networking with each other and not only networking with each other but also with external partners as well and getting to learn a little bit more about NCEH and ATSDR, we decided to keep this effort moving forward. And so the think tank has now taken an active role in guiding the process and creating a vision for continuing collaboration.

Year two of the think tank, we began characterizing environmental health issues affecting American Indian Alaska Native populations with the goal of bringing attention to those concerns through focused approaches. It was equally important that these priorities also aligned with NCEH/ATSDR's ongoing efforts as well. As such, the think tank agreed to - eventually agreed to five priority areas that are listed on the screen there; including food, resource extraction, infrastructure system development, climate and health, and clean air. And I also want to note that water is inclusive in all of those

priority areas, whether it's water quality, water quantity, or access to safe water, or it could mean training in the water realm, but they are - water is integral to all of those five priority areas. I also want to mention that these priority areas are not set in stone, nor are they the only priorities that my office will engage in. There will be flexibility in bringing attention to the issues that are relevant in Indian Country. However, because OTA is limited in terms of personnel and resources, it was important to set realistic goals for moving forward in a focused manner and the five priority areas was a doable start.

We are currently in the third year of the think tank and plans are to engage this year with external partners on environmental health topics, priorities and trends. This will include discussions around the five priority areas but other topics will most likely be introduced as well. And just based on interest from another initiative that NCEH has going called the National Environmental Health Partnership Council, the OTA is in the process of developing a customizable cultural awareness training course for external partners as well and I'll talk a little bit more about that course in a separate slide.

So before I move to the next slide, I wanted to just quickly give an overview about some of the benefits of the think tank thus far. So far, the OTA has completed a 3-5 year strategic plan that will serve as a tool for engaging with my divisions within NCEH and ATSDR and most importantly, it serves as a foundation for bringing visibility to the health disparities faced by American Indian Alaska Native populations and seeks opportunities to collaborate with others to address some of those health disparities. Another outcome or another benefit is that we've sought to include tribal representatives to serve on various national environmental health councils or committees, and for this round, we do have two representatives now on our partnership council and that's proven to be a very effective interaction that has been occurring. Again, the council includes national partners or members of national partners – partner organizations, academia, community activists, etc. Another outcome is that we really made a concerted effort to - for the think tank members to engage with program leaders and staff members within the ATSDR and NCEH divisions so that the think tank members are better informed about the mission and goals of the NCEH/ATSDR. One benefit of that or one particular benefit from that has been a pilot project that has been born between the Great Lakes Tribal Epi Center and three states to obtain some tribal data that will feed into the National Environmental Public Health tracking network which is a program that is - that has been established under NCEH. We are in the early planning stages of this effort, but I'm hoping that by the next TAC I'll have some more information to share on that. But that's just one example of how, through meeting and engaging with the different NCEH and ATSDR divisions, that we've given some visibility to the need for more data or tribal specific data. And as I mentioned earlier, I think another outcome again is that the members of the think tank will participate in the development and customization of a cultural awareness training curriculum that will be offered to external partners who engage with state and local health officials as well as health departments.

Just quickly to give you an overview of the Working Effectively With Tribal Governments training course, this course has been around for several years. EPA, the Environmental Protection Agency, had actually offered this course back in the 1990's, and at the time, it was a one-day course. When I came onboard back in 2008, one of the things that I realized was there was not a lot of education or not a lot of background about American

Indian populations in general, and so I took this course and revamped it a little bit with the goal of finding ways that we could really facilitate effective relationships with American Indian Alaska Native governments and tribal communities. Currently, it is a two-day course. I expanded it by a day, and we start with a really brief overview of American Indian histories and the policies that shaped that history. We have about seven to nine policy areas that had substantial impact on how federal government - American Indian governments operate today. So we cover that brief history and then we move into the overview of some of the current public health impacts and environmental health impacts that are affecting many tribal communities. And we end the discussion by talking about ways that we can work together to address those public health issues and concerns. It's a really fast course, but at the same time, I think it's offered that opportunity to engage with my colleagues on how we can work together effectively and to gain visibility on the issues that tribes face. When I first started this course, I had done it specifically for my colleagues within NCEH/ATSDR but CDC as a whole became really interested in wanting to attend that course and I oftentimes would get calls from people from other CIO's, other Centers, Institutes and Offices, asking if they could attend. I shared this with TSU, with the Tribal Support Unit, and they gave the blessing for us to offer it to all of CDC, and so it's currently offered through our CDC University. The good news is this year, we are tasked to do a one-day pilot of this course to the partnership council, so we're gonna shift the curriculum a little bit. We're in the process now of customizing that and we hope to offer that course at the end of September to national partner organizations.

And I was at a five slide maximum. I should've rebelled like everybody else did, but that's the end of my slides. But if you have any questions, I'm happy to try to answer them.

Lt. Governor Jefferson Keel: I think you did good. Thank you very much.

Annabelle Allison: Thank you. So the question was how often is the course offered at CDC/ATSDR, and it's currently two times a year, once in the spring and usually in the fall.

Annabelle Allison: At this time, no. It really is that mixture of individuals who have never been out to a tribal community before and have all kinds of questions about, you know, how they should prepare for a visit. I mean, we get questions like what is the correct term to use, is it American Indian, is it Native American, how do we refer—what are those correct titles. So oftentimes, we have those conversations, so it really varies from individuals with no experience to those with some experience who are just really wanting to hear more. And I think right now we've had over a hundred participants in the courses we've offered since the last three years.

Council Member Andy Joseph, Jr.: Really glad that CDC is doing this. I hope that other areas in health would do the same and maybe they could do some kind of a course for congressional staffers so that they understand that there's some real needs in Indian Country. Seems like - I work on the national IHS budget and it's been one of the poorest funded budgets that I've seen ever, and, you know, if some of our professional staff that

work in Department of HHS could pull together some kind of a report showing that there is really a true need in Indian Country, then maybe we wouldn't have to be worrying about our people so much.

Lt. Governor Jefferson Keel: Thank you, Annabelle. We appreciate that. You did very good. We look forward to seeing you again soon. It is lunchtime.

Annabelle Allison: Thank you.

Lt. Governor Jefferson Keel: We're getting close to lunch. The only person standing between us and lunch is Romana. No pressure there.

Romana Fetherolf: Good afternoon. I just wanted to give a few highlights from this morning's sessions. We discussed with CDC leadership the Tribal Engagement Plan, as well as the Public Health Associate Program, and they are interested in placing more public health associates at sites within Indian Country. And then Ms. Antone-Nez asked Dr. Arias if it'd be possible to get information on the 2015 targets—please refer to slide 3—and they said we will get it out to TAC members the link to that information. We had a big discussion on native specimens, and Lt. Governor Keel suggested a plan to get out the proposed policy to each of the sovereign nations so that they can discuss it and send back information to TAC members so they can discuss it at the next TAC meeting in February, and Stacy Howard will follow up with her staff to see if the timeline can align with that. And there was a lot of discussion on historical and future specimens. And then we had an update on the think tank and the Working Effectively With Tribal Governments course. We discussed a lot this morning, so if you – if I haven't mentioned something that we talked about, just let me know during break. Thanks.

Lt. Governor Jefferson Keel: Thank you very much. Before we go to lunch, I want to go over a couple of things. This afternoon we're going to have tribal testimony, and during the tribal testimony, on the inside cover of your binder, for those at the table, there are some guidelines. The one thing that comes to mind here that I'm reminded of is the door. It can be distracting and when tribal leaders or someone is giving testimony, very distracting for people to get up and leave the room or come in and out and having the door slam. So I'm going to ask you to once the tribal testimony begins to remain seated and be respectful of the folks that are presenting testimony. If you have to go out for some unknown reason—well, you'll know what the reason is, but if you must go, then we'll make sure that we do it as quietly and as respectful as you can because that is distracting and I've been in that position and I know how that appears. Other than that we will follow the guidelines, so come back prepared. I know that in the tab in your binder there is a list or the testimonies that are involved there. There are some that may come, some tribal leaders that may show up who want to speak, and we'll take those in proper and correct order. Other than that we will resume promptly at 1:15. Dr. Arias, do you have anything? Alright...

END. (LUNCH)

Tribal Testimony

Lt. Governor Jefferson Keel: This is the place where we hear from tribal leaders in their testimony. I want to remind you, once again, that as a courtesy to those who are presenting, if you must – if you have to leave the room, there's a door over there, we have a doorstop. That door is annoying when it slams and closes so just be respectful and try to be as quiet as you can. I have a couple of announcements before we get started. The TAC and the CDC/ATSDR, the leadership here – I'll get that acronym, there will be a dinner tonight at the Sweet Water American Bistro at six o'clock – that's the restaurant here at 6 pm - for the TAC and for any other tribal leaders that you want to bring along. Now, you will be paying for your meal, so be wise – well you get a little per diem, soor I could do that. Remember to pick up the questions from the listening session this morning on the discussion that we had on native specimens. It's at the resource table which is just outside the door, so pick that up and take it with you so we can have a good response. So at this time we're going to start hearing from tribal leaders. In tab 13, there are some testimony that are - have been provided. We'll go with those in order and then for those other tribal leaders who wish to testify, I do have a couple of ground rules, if you want to call them that. I would respectfully ask that you summarize your testimony. We have the written testimony already that's been provided. Some of the testimony can be quite lengthy, so if you could summarize your comments to maybe five minutes so that we have adequate time for everyone, and if you need a little extra time, we won't cut your mic off – we'll let you continue, but we ask you to be respectful so that we can get as much benefit as we can. So with that, I'm gonna ask for Fort Belknap Indian Community to begin.

Council Member Patty Quisno: Thank you. Good afternoon CDC/ATSDR leadership, directors and guests. Thank you for providing the Gros Ventre and the Assiniboine tribes of the Fort Belknap in Montana an opportunity to express our concerns about Centers for Disease Control and Prevention, and Toxic Substance and Disease Registry. My name is Patricia Quisno and I'm a councilperson of the Fort Belknap Indian Community Council and Council Oversight of Health Programs of the governing body of the Gros Ventre and Assiniboine tribes of the Fort Belknap Indian Reservation in Montana. The Fort Belknap Indian community consists of over 7,000 enrolled members for whom I am pleased to offer these comments. Tribal government, just like state and municipal governments, provide critical services, shape values and promote health environments. Tribal council is the elected officials responsible for our community members and ultimately the individuals most accountable for the health conditions of our tribal members who reside within our reservation communities. My testimony today is directed toward the public health issues affecting our communities. The following information is provided to you through the Fort Belknap Indian Community Council in collaboration with the Tribal CDC and ATSDR funded programs. Centers for Disease Control, many families and children living on the Fort Belknap Indian Reservation are suffering due to drugs, alcohol, sexual abuse and domestic violence that oftentimes results in child abuse and neglect. Priority needs to be given to the following areas for immediate address. Treatment of methamphetamines and prescription drug addictions for parents and caregivers, mental health services specifically for the treatment of trauma in adults and children. Victim advocacy programs, family treatment programs and community education for families and children affected by sexual abuse, rape and incest. Family and home-based services to provide supportive services to families.

Preventive services including youth mentoring programs, parent readiness programs, education services to parents and caregivers and wrap around services. In some statistics, white men living in Montana live 19 years longer than American Indian men and white women live 20 years longer than American Indian women. White women live seven years longer than white men and American Indian women live six years longer than American Indian men. This is a report on health of Montana DPHHS from 2013. Health issues important to the Fort Belknap Indian Communities, diabetes, foot care, 26%--this was as a result of a 2014 health survey of the Fort Belknap Indian Communities incidentally. Health issues important to the Fort Belknap Indian Communities, diabetes, foot care 26%, hypertension and heart 14%, fitness 15%, eye care 11%, cancer 11%, oral health 9%, chemical dependency 7%, stroke 7%. How concerned are you? Methamphetamine and drugs. Of the individuals surveyed, 63% reported that meth and drugs is of the most concern. Of the individuals surveyed, 63% reported that meth and drugs – I'm sorry, I'm repeating myself. Prescription drugs second, domestic violence third, ambulance fourth, and homelessness fifth. The nearest ambulance is located 35 miles away, and along with a lack of professional care providers at the local Indian Health Service. Adolescent health concerns, Fort Belknap Child Health Measures survey reports 54% of students surveyed are at risk for overweight and obese. Most students in grades 4 through 9th showed high blood pressure 20% greater compared to students in other grades. And this came from the Fort Belknap Reservation Child Health Measures in 2013. The United States code title 25 Sec. 1602 lists the special trust responsibilities and legal obligations that are the policy of the nation to fulfill in order to ensure the highest possible health status of Indians and urban Indians and to provide all resources necessary to effect that policy. Along with having another trust responsibility, to raise the health status of Indians to at least the level set forth in the goals contained within the Healthy People 2010 initiative, or successor objectives. Also with providing funding for programs and facilities operated by American Indian tribes and tribal organizations in amounts that are less than the amounts provided to other programs and facilities operated directly by the service. In addition, after this testimony was backed, I did get a report from our environmental department regarding our drinking water, septic and sewage lagoon system that didn't - that I hadn't received before. Since the flood of 2011, the Fort Belknap Indian Community has seen an increase in MRSA infections, or methicillin-resistant staphylococcus aureus bacteria. These are present on the body in the form of boils usually on an individual's torso, especially the buttocks region. Many homes in the past and some homes presently have individual domestic water wells and individual septic systems and tile fields to rid their home of sewage. These homes are located in remote areas where water mains and sewer systems are not present. When the flood of 2011 occurred, many homes in adjacent property were under a foot or more of water - of flood water and sewage from septic systems and tile fields were disturbed and carried downstream, and domestic water wells were compromised. It is our fear that this flood event may have played a big part in this and other types of infections and is present in the surrounding soils and the domestic drinking water sources, which people use for drinking, bathing and cooking. With climate change a reality, Fort Belknap has seen an increase in precipitation in the form of snow and rainfall. The flood of 2011 is by no means the only extreme flood event we will see in our lifetime. In 2013, flooding occurred in many areas of the reservation but not to the extent of the flood of 2011. More funding sources are needed to address concerns about the drinking water and

sewer systems at Fort Belknap and other tribally run utilities. Most reservations including Fort Belknap are responsible for more than one drinking water system on their reservation because they're comprised of more than one town, village or community. For instance, at Fort Belknap our local utility is comprised of 6.5 full-time or FTE people. A director, a half-time utility clerk, water plant manager, water plant operator, operator in training, solid waste drivers, we have two of them. These individuals are responsible for sewer, water and garbage pickup, transfer for four communities. Staff is spread thin, constantly pulled in different directions to deal with water and sewer line breaks, maintenance of water pump houses and pumps, operation and maintenance of water treatment plants, dealing with new housing or businesses, cleaning and flushing fire hydrants, cleaning sewer systems, maintaining water tanks, ordering or renting equipment, supplies, deterring septic companies from polluting on the reservation, lagoon maintenance and so forth. Funding is not adequate to cover all costs associated with running a utility for four communities, yet they are expected to and attempt to do everything in their power to address all issues they are faced with on a continuing basis. The result is high staff burnout and staff turnover and inadequate funds to run an efficient utility. In addition, in order to meet our new drinking water requirements, funds are spread even thinner for new equipment, chemicals and sample analysis. Additional sources of funding are needed to address the constant barrage of issues tribal utilities face on a daily basis. Thank you again for the opportunity to provide our perspective.

Lt. Governor Jefferson Keel: Thank you. Now we'll hear from the Navajo Nation.

Ramona Antone-Nez: Thank you. Honorable tribal leaders, distinguished federal officials and guests. It is an honor and a responsibility to represent the Navajo Nation at this official tribal consultation session to share testimony on several accomplishments, critical concerns, and to provide recommendations that specify - specifically pertains to CDC and ATSDR. Navajo area delegated representative Mr. Rex Lee Jim, Vice President of the Navajo Nation, sends his kind regards and apologizes for not attending today's important tribal consultation session. I am Ramona Antone-Nez. I am Navajo and Iroquois Oneida, Director of the Navajo Epidemiology Center and serve as the authorized representative for Navajo Nation. The Navajo Nation is building our public health infrastructure to establish a state-like Medicaid system, medical school and cancer institute. These are major initiatives requiring funding, strategic planning, technical assistance and capacity building and workforce capacity development. In preparing for these major initiatives, the Navajo Division of Health has developed legislation to become a department of health. Upon Navajo Nation council approval, the department of health will be authorized to monitor, enforce, regulate, evaluate and coordinate the public health system on Navajo Nation. The Navajo Nation's government-to-government relationship with the United States is essential to access federal funds, assess technical assistance to evidence-based practices, disease prevention, epidemiological investigations, strengthening our public health infrastructure and emergency preparedness. We provide testimony- we provided testimony during the February 2014 meeting and requested a current status on the Navajo Nation's Veterinarian and Lifestyle Program reports and sera samples that were sent to CDC on July 23, 2012. And we remain very interested in finding the results to those findings. What it was was dog serology that would look at the puppies that were vaccinated for rabies, and we want to protect our people from this particular vector borne disease, and

we'd like to have a follow up on that request. Research such as the Navajo Birth Cohort Study which is funded for three years through a cooperative agreement, we would like to – we appreciate that. However, we continue to advocate the need for a long term study on the affects of uranium contamination, exposure and environmental health cleanup efforts. Regarding recommendations and conclusion, the Navajo Nation offers the following recommendations to address and resolve our health disparities and concerns. The CDC/ATSDR provide funding directly to tribes. In order to streamline funding processes and minimize the time it takes to receive and expend approved fundings, information was shared at the TAC that this recommendation be brought through as a congressional process. Therefore, we respectfully request technical assistance on procedures in order to process tribal requests to Congress in terms of direct funding. According to the ACA, Indian Healthcare Improvement Act 2010, the Tribal Epidemiology Centers must have direct access to tribal health data from federal agencies such as the Indian Health Service and CDC, state, and local sources. We appreciate your assistance in that matter. The CDC needs to increase and expand its support for chronic diseases such as cancer, diabetes, obesity and cardiovascular disease, including cancer screening, wellness, obesity control and prevention, education and screening for diabetes, screening and education for LDL, blood pressure and obesity for prevention for cardiovascular disease. We also acknowledge and appreciate the recent increase in funding opportunity announcements that were provided to Indian Country, and we look forward to results from those reviews. Another recommendation is to address the Urban Indian Alaska Native health needs for health education and promotion through funding allocations. As intentional injuries are the leading causes of mortality on the Navajo Nation, we recommend an increase in funding allocations from 2% to 3% for the injury prevention programs. In addition to these written testimonies, I'd like to also add that to recommend the financial support for the Tribal Advisory Committee and technical assistance to have a tribal caucus a day prior to the CDC meetings and consultation. In closing, we ask for and look forward to your written response. We also would like to express our deep appreciation to the CDC/ATSDR Office of State, Tribal and Local and Territorial Support officials for your commitment to consult with tribes on our program policies and relating to matters that affect the tribes. Thank you for your attention and I want to please note that we do have a written—what I've done is a brief overview. Thank you.

Lt. Governor Jefferson Keel: Thank you for that summary. Your written testimony is contained on the record and in the file. There may be questions for clarification at some point, but it will be at the conclusion of the other testimony. Now, is Chairman Steve Cadue from the Kickapoo tribe here or his representative? Kickapoo tribe? Then we will go to other tribal leaders who wish to present testimony. Once again, please identify yourself and the tribe that you're representing and please summarize your comments. Thank you. Cathy?

Director Cathy Abramson: Cathy Abramson from the Sault Ste. Marie Tribe of Chippewa Indians, and I represent the Bemidji area. The following topics are a list of reoccurring issues that have been noted in the last two years by tribes, tribal organizations and tribal serving organizations and partners. This list is being brought to the attention of appropriate tribal leadership for discussion and consultation between American Indians Alaska Native Tribes and the federal government, including the CDC, HHS and other

federal agencies that structure funding and projects to be awarded to successful grant cooperative agreement applicants. We look forward to a positive medium to provide feedback to these organizations in order that the opportunities for federal grant funding for tribes and tribal organizations be utilized in a manner that proves effective and worthwhile for all parties involved. Concerning topics include data and evaluation requirements do not reflect the unique issues that face tribal communities when selecting, adapting, implementing and evaluating programs. The emphasis placed on measures in reporting the population reach of intervention strategies creates a disadvantage for tribes that have a small population size and sometimes places additional requirements on tribes that may not be expected of county or state projects. Funding opportunity announcements often list tribes and tribal organizations as being eligible to apply but fail to include consideration on how some of the grant requirements might be difficult to apply in a tribal context and therefore a disproportionate burden is placed on tribes to fulfill requirements versus other types of applicants. The best example of this is requirements for population level surveillance data. Whereas many state and county health departments have various sources of population data and have epidemiologists on staff to conduct this work, most tribes do not have these resources and often have to dedicate most or all of their evaluation funds to fulfill this requirement of the grant. A possible solution could include more tribal health professionals in the program development planning, create more funding opportunities and programs specifically for tribes and tribal organizations. Another is funds intended for tribes and tribal organizations are not reaching the tribal communities, or award of grant funds intended for implementing with tribes or tribal organizations to universities or other organizations whose indirect costs consume up to more than half of the operating budget and with budget allocated a tiny fraction of funding that goes directly to tribes for services. Many of the funding opportunity announcements have such rigorous requirements for existing capacity to implement programs that only a small number of tribes are competitive for funding. These tribes tend to have – to already have significant capacity to carry out public health projects. There is a concern that this is creating even greater disparities among tribes because the tribes that have very serious needs for funding to build capacity also tend to be smaller and more rural. Recent funding opportunities for tribes where eligible to apply had requirements that prevented tribes from applying directly. Also, there's a lack of understanding and cultural competence of grant reviewers. There are concerns that grant application reviewers are not knowledgeable of tribal communities broadly, and tribal public health systems specifically. Some of the comments that have been received from reviews indicate a lack of understanding for tribal sovereignty and tribal culture. Possible solution would be to include reviewers in the review process that have solid experience working with tribes and that understand tribal sovereignty, tribal programming and program implementation issues. Now, CDC distributes funds to carry out public health functions through non-competitive and competitive mechanism to states, non-profit organizations, academic institutions and others. Tribes and tribal organizations have recently observed increased inclusion as eligible and qualified recipients yet often lack the population numbers and resources necessary to submit a competitive application. It has been noted that CDC is making attempts to improve funding outreach tribal populations; however, the larger fund pools disseminated through states aimed at collection of vital statistics, disease registries, environmental public health tracking, maternal child health block grants and emergency preparedness are just a few examples of funding streams that may or may

not reach tribal communities. Therefore, it is recommended to consider the following. Engage a study of availability and application of federal funds distributed through states. Inventory all funding sources currently disseminated through states, statutory and discretionary. Sort by non-competitive and competitive. Identify and document eligibility criteria for non-competitive and competitive funds. Investigate state utilization of funds to determine funds earmarked for tribal and urban American Indian Alaska Native populations. Collect available outcome data describing American Indian Alaska Native benefit from state application of CDC funding streams. Alright - and then develop a strategy to improve access and funding amounts to directly impact American Indian Alaska Native rural and urban communities. Strategies may include fund tribes, tribal organizations directly for population based public health activities and infrastructure. Two, develop selection criteria other than population numbers. Example, the number of tribes served, geographic distribution, prevalence of health disparities. Three, in order to help tribal communities be more successful in accessing funds establish a more open customized and equitable technical assistance system during the grant application process. With funding for public health activities administered through states, require states to declare and provide evidence of how they will include tribes in funding resource distribution in both non-competitive and competitive funding streams. And then develop an accountability mechanism and track state use of funds to benefit rural, tribal and urban communities. Thank you for listening and thank you for your time.

Lt. Governor Jefferson Keel: Thank you, Cathy. And we'll now go to Andy Joseph.

Council Member Andy Joseph, Jr.: My name is Badger, I'm Andy Joseph, Jr. from the Confederated Tribes of Colville. I sit as a delegate here at large and what I'd really like to see is the traditional foods and medicines be reinstated. To me, that's something that is real serious to our health and just seeing today the resistance threat that people are having to deal with with antibiotics. To me, I think some of our own traditional medicines can be a replacement and can be used to help actually cure some of our people that are dealing with the hardships of the different illnesses. In my state is one of the states that the marijuana is brought in and I think I'd really rather prefer that the federal government control the medicinal part of that medicine and just for my own family, I mentioned my sister earlier dealing with her cancer and stuff; if it wasn't for our traditional foods and medicines and her using the medical part of marijuana, I don't think she would be here today. We seem slight about the different legal medicines that are out there that are causing a lot of our people's deaths, the opiates and all that other stuff that I imagine if my sister was using that and if I went to go visit her, she wouldn't be able to communicate with me. The medicine that she is using allows her to be able to eat, and that's one of the biggest problems with our people that's dealing with cancer and gone through all the chemo and the radiation is they lose their appetite and a lot of them end up leaving us a lot sooner than what they need to. I'd hope that the CDC would look into that a little more, and I've heard testimony of children that have to deal with seizures that there's a time at the beginning stages of growing that marijuana that when they use it before it reaches the high THC content that those children that use that don't have any seizures anymore. And to me, I think that's really important for our children, and I just wish that there'd be more studies dealing with that. Like I say, I'm not for legalizing it or anything, but I just think that I'd really rather the government control the medicine part of it. Emergency preparedness. Right now at home, we're dealing with a big massive fire

on our reservation and emergency preparedness and funds—and we've got our people deployed and the need for more resources when these emergencies happen, to me, are real - really necessary. With the limited funding that IHS and what the state might give for some of the people that are on the lines of public health nurses have to go around our reservation to try to help our elders deal with all of the smoke that they're breathing in and they might have asthma and different illnesses and the need for that emergency type of funding—I mentioned earlier, some of our public health nurses, because they're so poorly funded, that they dig in their own wallet and purchase supplies to do their work because they care enough for their people. I'd like to see more funding go into emergency preparedness for our tribes that have these emergencies. Another issue that I brought up a little bit earlier, the toxic waste from the mines. We have the Columbia River and the Tech Cominco's dumping their slag into the river, and the fish and all that water filters down into our territory and my worry isn't just for my tribal members but it's for the whole state - both Washington and Oregon because it makes it down to the ocean. Another thing is when there's smelter, and it's probably smelters from all the different mines in this country, they give off this dust that goes into the air and drifts. There's been studies that it drifts from way up into Canada and it comes down into Washington State and it don't make it over the Cascade Mountain range but it circles around and actually goes clear down to where Shawna is from in Umatilla and it goes up and over the Rocky Mountains, and that dust settles into the creek beds and the water streams that flow into our lakes where our fish and wildlife have to consume it. And we're finding deer with weird spots in their meat and fish are contaminated - get contaminated with that. In some areas, they don't allow their people to eat the fish in some of those lakes. So to me it's really toxic, so that's cutting into what a lot of our people use for subsistence. Another issue that come to my attention also is - is accreditation. I think it's something really important to have all of our health facilities accredited. We need added funding to be ahead of that game. I think before long it's gonna be mandatory and we already see that with the MOU, with IHS and the VA. The VA requires our health programs be accredited in order to bill for that service, so we need to have, I guess, extra funding to be ready for that. I agree also with Cathy's testimony on funding. To me, I would hope that the funding would be coming directly to tribes, and I would use like the IHS system for distribution. I think it's pretty fair to use that system. Some areas, like the Portland area, are—they used to call it CHS. It's purchased and referred care only systems. We don't have IHS hospitals like some of the other areas do, so we have to contract out all that extra work that, you know, when you have more urgent conditions. To me, they have - IHS has a system that kind of balances it out so that we get a little fairer treatment budget-wise. Before, when H1N1 came, and it was a big scare—I mentioned this earlier—that the funding came - or the vaccinations came through the state system, and I believe the people were so scared in our counties that they served themselves. Like I said earlier, my daughter was carrying, and she was like the number one priority at that time. She couldn't get a vaccination from our own county, so she had to go across the river to a neighboring county and to me, some of our schools that were in our county got vaccinated from a neighboring county. To me, it just wasn't a fair system, and I would - on something like that, if we have to have those vaccinations, I would go with the IHS system so that we know that we're gonna get what we're supposed to get for our people. We lost some people with H1N1. We have to care for their children now and their families because they don't have a dad there to help them with their income. To me, that's really injustice when the

county and the state system probably would've protected that family. That's all I have for now, and thank you for this opportunity to testify.

Lt. Governor Jefferson Keel: Thank you, Andy. Are there any other tribal leaders who would like to present testimony? While he's getting his testimony together, once again, if there's a tribal leader in the room who wishes to testify, I would ask that you would summarize your comments. Please keep them within the five minute time range if you can. Thank you.

Chairman Herman Honanie: Thank you, Lt. Governor Keel. This is Herman Honanie, Chairman of the Hopi Tribe, and I just wanted to make a statement. Today and yesterday, we heard many updates by CDC and other respective entities, all are directed in working with and for tribes across this country. Many issues are unique or specific to respective tribes. Therefore, sometimes it means that tribes may be selective in working with programs of CDC. However, I believe leadership of CDC have committed their agency to work with and alongside tribes. This morning, we heard CDC's goal is to provide the tools to tribes, so that tools - so that tribes can help themselves. One idea that surfaced is the TAC should consider supporting the idea that CDC and IHS, the HHS merge to work closely or together to better focus on issues and concerns that both agencies maybe face or jointly responsible for. In this way, perhaps these issues are common to many tribes can be better or effectively addressed and/or resolved. The ongoing issues of diabetes, breast cancer screening services and/or prevention, tobacco use concerns, environmental disease in general, health prevention concerns, strategies/approaches, traditional foods programs, and so on, was spoken to. Much information stating progress made accordingly was shared as well. As tribes, we need to readily embrace these efforts and programs of CDC to improve our health status, as well as to contribute to addressing or resolving those issues that we face at home. For example, Native American specimen collection or management is important, and CDC is being asked to develop appropriate policies. However, as sovereign tribal governments, we also have an obligation and responsibility to ourselves and people to be proactive in this and other areas as well. The TAC needs to continually advocate on behalf of our tribal people; advocate for continued and increase in funding for programs for tribes on tribal lands, continued consultation in all areas of health and related concerns must continue. My people long ago stated that we must not let go of the duty and responsibility the federal government has to our people, but we must do our part to help ourselves to build stronger societies as we embrace the services of CDC, IHS and the entire federal government. Through these recently developed relationships through TACs and the STAC and others, these are means for tribes to get into the doors. Tribes will continue to solicit resources, but as we do, we need to support CDC and IHS so that congress and the leadership of this country will continue to provide or allocate the resources we all need. In closing, I'll remind us all to practice our traditions, pray and live life to endure. Thank you very much.

Lt. Governor Jefferson Keel: Thank you very much. Is there any other tribal leader who wishes to testify? Go ahead Chairman Devers. Remember our conversations?

Representative Chris Devers: I'll keep it short. I'll keep it short. Chris Devers from the Pauma Band of Luiseno Indians representing Southern California Tribal Chairmen's

Association. To begin, I want to thank representatives from CDC for hosting this. But with the good also comes the bad. Now, I understand that there is no representative from California and that is something that, I know there's another representative, Virginia, from Northern California, California Rural Health Board, and myself that are here today, but there's also 111 - 113 federally recognized tribes in California. And one of my comments is as representatives to the TAC, what voice do you carry? Do you carry or is – do you carry the voice for all the tribal nations within your region? If so, by what means do you do that? I was brought up somewhat old school, that I respect the tribal leaders that may be three or four miles next to me, and their voice is important. And without their permission, I can't carry their voice. So my thought is—and Captain, we talked about this the other day—is I'm pretty sure California would welcome the presence of CDC in our areas to assist tribes in health issues. How do we accomplish that? We know that there's a lack of funding out there for travel—even for a TAC representative to interact with the tribes that they represent. I know Lt. Governor Keel – I know he knows fully well what it's like when you represent one large entity and how do you carry that voice of that large entity. So how do you carry that voice with 113 tribes with different issues that span from different regions, different areas, different environments throughout the state of California. But today and yesterday, there was some good—Virginia, this thing went out. I had my notes here and they just went blank-- there was definitely, just on a personal note, when I came here and my perception of what CDC was, the Center for Disease Control, you know, I thought you were talking about impacts that are out there like the Ebola strain and all these other swine flu and these other contagious disease. And then I realized that you're involved in a lot more than that, and I think it's important that the tribes in California know that. And that - but how do we get that message to them other than we talked about the samples—what do they call them—the specimens and everything that's out there, somebody had to come out there and get them. And by all means, somebody should come out there to return them. So there's some - expectations that are out there. Now, funding I know is important and it's critical because there's always a lack of it, and that HHS, the CDC, all these other federal entities—sometimes, to me, it seems like they work in silos where they're focused on what they're doing today and a little bit of tomorrow, and then come to find out there's a lot of similar agencies doing the exact same thing, working on the same issues. We're getting duplicate results, duplicate studies. How do we merge everything together so that everybody's working for one large common cause, you know, the health of Indian people. How do we get that out there. Emergency preparedness. You know, we've all, in one way or another, have faced that. I've had the unfortunate - I was unfortunate enough to face two wildfires in southern California. In 2003, we had a wildfire out there that was large. And I thought I would never see one in my - again in my lifetime. In 2007, we had a larger one that really was devastation – provided - devastated a lot of tribes. But now we're going through the drought issue. There's bills being presented in the California legislature about the use of ground water and the reservoirs and everything we have, but the tribal people still need water to drink, and push come to shove, the quality of that water could be in question because you're gonna get to a point where you're gonna drink anything that you can that you can find. And that's the people, that's the two leggeds. You know, we all have all of our brothers and sisters of the animal kingdom that need to survive. What are we doing for them? How do we protect them? The salmon kills that I envision are gonna happen in northern California this year for those salmon tribes. Gonna be devastating to them. So there's a

lot of things out there that I believe CDC can play a role in but we've got to merge your agency with the tribes. The consultation—I may be a little bit old school but it's tribal leader, government to government, and an effort should be placed to accomplish that. I've been involved in a lot of different entities that, sometimes, we take on a little bit more than we can chew because we don't realize how hard it is to be able to get out there and communicate with 530-some odd different tribes, and the ability to do so. So my comments and my concern is is how do we develop that relationship government-to-government, health-to-health organization in the state of California, and I look to this board and I look to the representatives of CDC to assist in doing that because in February, I think when the next board meeting is, I'm hoping that there will be a lot more representation from the tribes in California. Whether we have somebody sitting at the table or not, to me, is important but it's not life stopping, but it's the tribes' ability to sit down and talk with the tribal leaders and CDC about issues that pertain to California. Thank you for your time.

Lt. Governor Jefferson Keel: Thank you very much. If there are no other tribal leaders who wish to present testimony—there is one.

Loi Chambers: Loi Chambers, Grand Traverse Band. The question I have here is I'm noticing that we're seeing a higher incidence of cancer in our tribal members, and I wanted to know if the CDC has any surveillance type data as to what is causing this. And what we're seeing is cancer in a younger population of people that it's affecting, and we, as a tribal health facility, know that we have these patients with cancer, but I wanted to know if the CDC had any type of surveillance data for tribes in general as to what are the types of cancer that is affecting Native people out there, and if they know of any causes for this disease that they could provide or if there is somewhere that we can go to find the data so we could further develop programs.

Lt. Governor Jefferson Keel: Would you repeat your name for the record?

Loi Chambers: Loi Chambers. I'm with the Grand Traverse Band Health Department.

Lt. Governor Jefferson Keel: Thank you. Those questions will be presented to CDC and I know that they'll have a response.

Council Member Leslie Sampson, Sr.: First of all, I would like to say thank you to these ladies. They put a lot of great deal of time for this meeting. I want to thank Vice Chairman Antone as for you Lt. Governor. I have great admiration and great respect for native leaders like you, and ladies and gentlemen around this table, thanks for the information and your thoughts I can bring forth to the tribe. I will begin my testimony. Hello, my name is Leslie Sampson. I represent the Noorvik Native community as a tribal councilman. I live in the bush Alaska. Our village has about 688 people. Where there is no road system, our means of transportation is by air, which is year round. Summertime, we use boats and ATV, and in the winter, we use snow machines. I want to talk to you a little bit about tobacco use. The high rate of tobacco smokers in rural Alaska, which I'm from, top the charts when compared to all other countries around the United States for 2012, according to a recent study from the University of Washington. Researchers from the University Institute for Health Metrics and Evaluation dissected

data from their annual telephone survey health survey conducted by U.S. Centers for Disease Control and Prevention and gratified it's based on counties and sex 17 years from 1996 to 2012. When you look at it county by county you see the disparities. Northwest Arctic borough have the highest rate of smokers in the United States, estimated about 41% of males and females regularly use cigarettes in 2012. Double the percentage in Anchorage and Fairbanks. These two cities are the two biggest cities in Alaska. Nearly 7,800 people live in the Northwest Arctic borough in areas slightly smaller than the size of Indiana, that sits along the Kotzebue Sound. Kotzebue is our hub town. An annual budget for the state Department of Health and Social Services of about \$375,000 fund the borough tobacco prevention programs, run by the tribe-operated Maniilaq association. About 912 people have joined the association cessation programs since 2009. Kotzebue and surrounding villages, many people still consider smoking cigarettes the norm and that's something they're trying to change. The Association Prevention Manager and Coordinator posted up metal signs around the borough, they read help protect the air out of respect for elders and the love for children and nature and we hold on to our culture a lot. So it's kind of weird because our culture doesn't include smoking. About one of three Alaska Native adult smokers compared to one of five Native adult according to Alaska Tobacco Facts 2014. The statewide report from the state health department. Since 2012, eleven of the twelve communities serve by the Maniilaq Association passed work place smoking ban. That doesn't mean people have to put out their cigarettes. Alaskans die annually from the direct affects of tobacco use, then from suicide, motor vehicle crashes, chronic liver disease, cirrhosis, homicide, HIV/AIDS and influenza combined. Besides smoking, health officials also link the death of chewing tobacco and iqmik - mix of punk ash and tobacco use like chew and poppy in the Yukon Delta, Yukon-Kuskokwim Delta. Data shows that the rate of smokeless tobacco is highest in southwest Alaska. To combat tobacco use, the legislative funnels money into the state health departments, Alaska Tobacco Prevention and Control programs. The budget signed by our governor in March includes nearly \$10.4 million in the program - for the program. About \$750,000 less than last year. The funds come from the Centers for Disease Control and Prevention, tobacco taxes, the state general funds and the Tobacco Master Settlement Agreement, a medical payment lawsuit involving 46 states and the four - big four tobacco companies. The companies agreed to curb deceptive marketing and pay in perpetuity millions of dollars to the state. The Tobacco Prevention and Control program dispersed half - about half of its budget to 28 agencies across the state in fifteen grants. It's so alarming. It's so sad to hear, and even sadder to say that our borough has the highest rate of tobacco use in the United States. Senator Begich is a member of the State Appropriation Indian Affairs Committee and has been pushing for increased funding for Indian Health Service. Their agency has been grossly under funded for too many years and making sure Alaska tribes and Tribal Health Organization deliver medical - vital medical care, are fully compensated. Thanks to pressure he put on Obama administration and secure fully funded contract support cost for this year and Obama has requested full funding for 2015. The federal government has trust responsibility to provide healthcare for it's nation's first people and must honor its contractual and legal obligation to tribes who chose to compact and contract with the federal government. The money Indian Health Service have settled 22 claims with Alaska tribes resulting in payments of nearly \$200 million, and .Senator Begich will be monitoring the settlement process closely and making sure that all Alaska tribes are paid in full. The Indian Law and Order Commission report a roadmap of

making Native Americans safer. A disturbing picture of cycle violence, addiction and abuse in many Alaska rural communities. More than 95% of all crimes in rural Alaska are attributed to alcohol. The alcohol related suicide rates to Alaska village is six times the national average. Alaska Natives are the ones who suffer from the highest rates of rape in the country. One of two Alaska native women experience physical or sexual violence. Local communities must have support to deal with public safety problems and consult with tribal leaders. Senator Begich introduced the first version of his legislation to Safe Families and Village Act in 2009. Last fall, he introduced a revised version of the bill. This bill does not preempt state response and authority. It complements it. The bill allowed tribes to create solution that works for our communities. The Safe Village Bill also repealed their revisions inserted in the Violence Against Women Act that prohibits Alaska tribes for issuing and enforcing domestic violence protective orders against non-members and non-native. The repeal of this prohibition will allow tribes, the state of Alaska and stakeholders to further strengthen domestic violence protective orders in rural Alaska. Suicide is now the 6th highest cause of deaths in Alaska. Too many people have lost loved ones and friends to this terrible epidemic. To help the medical community better identify and understand cause of suicide, our senator introduced the Suicide Prevention Research and Innovation Act, that's called SPRINT in February 2012. It provides funding for the National Institute for Mental Health to conduct targeted research on suicide prevention over the next five years. The funds will be used to help experts learn more about the triggers of suicidal behaviors. In addition to the SPRINT Act, the senator requested five million for grants to tribes struggling to deal with the highest rates of suicide, substance abuse, mental health problems in our youth population. Many Alaskan organizations are doing great work statewide, but they still need to do more to prevent suicide in our rural communities, especially among our Alaska Native youth, mental health community will work toward the day when no family will have to suffer through the loss of a loved one as a result of suicide. Thank you.

Lt. Governor Jefferson Keel: Thank you very much. If there are no other tribal leaders, I was just reminded that the TAC or other tribal leaders, if you're interested in presenting testimony, you have up to 30 days to do that in writing. If you have a copy of written testimony today, the CDC representatives will take that with them. But we have another tribal leader.

Chairperson Aaron Payment: I didn't introduce myself to you earlier, and I apologize. My name is Aaron Payment. I'm the Chairperson for the Sault Ste. Marie Tribe of Chippewa Indians. I also serve as the vice chair of Inner Tribal Counsel, United Tribes of Michigan, Midwest Alliance of Sovereign Tribes and NCAI for the Midwest region. So I'm the chair of all vices. Earlier, I forgot to mention when they were doing the studies of the skulls to measure the capacity for the Indian brain—and the Ojibwas will understand this joke—but if they would've measured by our skull size, the Ojibwas would be the smartest. Big heads. But anyway, so I also serve on STAC, and I'm now the co-chair of the HRAC - Health Research Advisory Council. So I didn't have a prepared testimony but real briefly, I would be remiss because there is a public health issue, and I do see it as a public health issue that goes unaddressed. So we have an education - my background is in education. I'm a high school dropout, but I'm this close to having my dissertation done in education leadership. My sister is a high school dropout. She's this close to having her Ph.D. in evaluation research. And so Native Americans drop out of high

school today at a rate of 50% and that's nationally. Oklahoma's got the best graduation rate and I think that has a lot to do with the number of Natives in Oklahoma and the impact on the public system in Oklahoma, I think in terms of raw numbers and percentage of the total and the ability to affect public issues. But when I left my previous career to go into tribal governance back in the early 90's, the dropout rate was 50%, and when I left tribal office for a couple of years and went back to school, I thought well, I'm gonna study issues related to Native Americans, but certainly they fixed this problem. But it's still 50%, the dropout rate is still 50%. So we really have not gained ground in about 25 or 30 years. My tribe has our own school. We have a BIE school and at it, we do reverse RTI. Who knows what RTI is in education? It's Response to Intervention and it's a focus in looking at your distribution of your students and the top 20 are supposed to need intensive services; but what we do is we flip that triangle upside down so we focus and provide the intensive services on actually all students. We qualify all students for title one services. One of the particular areas that I think that gets missed in public schools is the issue of learning disabilities, and where this ties into where I think there's some needed attention from CDC is the issue of autism and the increased rate of autism that we're finding in Indian Country. I think it's always been there but I think that our detection of it has not been very good and there's a reason for that because with ID - IDA, with the education law, once you have a diagnosis, then you have a legal responsibility to provide accommodations. And so schools aren't ready and they're not typically willing to identify that area. So there is an environmental dimension to autism that I think deserves a focused of attention, and I brought this to HRAC and I think under CDC we don't know what causes autism today. There's a lot of speculation about immunizations and environmental factors in your community. I do think there's a relationship environmental factors in your environment, in your community but it's an issue that I think deserves a focused of attention. So if that can be carried forward and I can write up something and submit it, hopefully within that time period that you mentioned earlier. And then lastly, earlier, there was discussion of the increased rates, and I think it was - the multiple was four times the rate in Indian Country for the introduction of certain drugs. In our community when I came back to office, we're facing a crisis. We have for probably the first two or three kids a month in our community were dying of overdoses, black heroine. So there needs to be a focus of attention, maybe a cross pollination in CDC with DOJ to try to figure out how to deal with this issue and the trafficking that's coming in from the cartels. So thank you for your attention and I'm glad the Ojibwas laughed at that joke earlier with our big heads. Thank you.

Lt. Governor Jefferson Keel: Thank you very much. I'm glad I'm not an Ojibwa. He didn't get it. Okay, Dr. Monroe, did you have any closing comments?

Dr. Judy Monroe: I just want to thank everyone for your engagement, for your testimony, and we'll take all of this back to all of our experts in CDC. So just thank you all very much and thank you Lt. Governor Keel for your leadership and congratulations again on being vice chair.

Lt. Governor Jefferson Keel: Well, thank you. I wasn't expecting it, but I'll do the best I can. Once again, I'm going to remind those tribal leaders if anyone wanted to submit written testimony, please submit it to the tribal support box at tribalsupport@cdc.gov within 30 days from today, and this will allow all testimony to be part of the record. Once

again, I want to thank Dr. Monroe and Dr. Arias for being here. Thank you for your support. Captain Shaw, she has something else to say.

CAPT April Shaw: I thought I could get off the hook from having to speak today. I just wanted to remind all those that are going on the site visit tomorrow morning that it'll be at 7:45 in the morning. That we'll meet in the lobby to go by bus. So we look forward to going on that site visit. Thank you.

Lt. Governor Jefferson Keel: With that, I thank you for your attendance. Go enjoy the afternoon and remember, TAC leadership, there is a dinner tonight at 6:00 p.m. So see you then.

END.